A SPACE OF THEIR OWN: IMPROVING SOCIAL SUPPORT AND QUALITY OF LIFE FOR ADOLESCENTS AND YOUNG ADULTS WITH CANCER

A Dissertation

Presented to the Faculty of the Graduate School

of Cornell University

In Partial Fulfillment of the Requirements for the Degree of

Doctor of Philosophy

by

Kathryn Sandra Peditto

August 2019

A SPACE OF THEIR OWN: IMPROVING SOCIAL SUPPORT AND QUALITY OF LIFE FOR ADOLESCENTS WITH CANCER

Kathryn Sandra Peditto, Ph. D., EDAC

Cornell University 2019

As cancer remains the leading disease-related cause of death in adolescence, healthcare officials must consider the influence of facility design on peer-to-peer social support and quality of life, while accounting for an adolescent's unique and changing needs. Both the stress of treatment and the environment in which treatment occurs can influence adolescents during a time of significant social, biological, and cognitive transitions. This dissertation spans developmental psychology and health design to inform specific design guidelines to improve quality of care for adolescents and young adults (AYAs) with cancer.

A phenomenology first addresses the gap in AYA research by exploring the experience of cancer during adolescence and young adulthood. Interviews with AYA participants assist in understanding the needs of patients and the structures that support or impede their experience.

Following the interviews, a questionnaire is developed to investigate the mediating influence of peer social support on the relationship between features in the built environment and improved quality of life. Multiple regression demonstrates the value of certain environmental characteristics as they influence social support and quality of life.

A third study extends the results of the questionnaire through focus groups with AYA participants to further elucidate the preferences of young people in the built environment.

The features deemed most influential, along with the evidence for their value, are presented in a set of design guidelines for retroactive and future facility design. Through translational research design, this dissertation will have a wide applied impact on patient quality for a currently under-studied population.

BIOGRAPHICAL SKETCH

Kathryn Peditto was born in Annapolis, MD. After completing her schoolwork at Indian Creek Upper School in 2011, Kati attended the School of Engineering and Applied Science at George Washington University from 2011-2013. She received a B.A. in psychology from St Mary's College of Maryland in May 2015, where she completed a capstone thesis on infusion pump keypad design. Her previous experience investigating alarm fatigue at Johns Hopkins Hospital in 2014 sparked her interest in design research in healthcare settings.

In August 2015, she entered Cornell University in the Department of Design and Environmental Analysis, pursuing a Ph.D. in human behavior and design. After leading a run from San Francisco to Baltimore in summer 2016 with the Ulman Foundation, Kati noticed that AYA patients were often treated in pediatric settings with little access to peer support. This experience sparked her doctoral research investigating the influence of the built environment on social support and quality of life for young people with cancer.

In 2016, I ran across the country with the Ulman Foundation's 4K for Cancer. It's a 4K tradition to champion the cancer community through daily dedications. Each morning during the summer, 4K runners and bikers write names in Sharpie on their legs. The most challenging days on the road pale in comparison to the stories of strength and courage behind these names.

This degree has been a marathon; this dedication section is my Sharpie leg. It has been an honor to run for you:

JoAnn, Megan, Beckie, Evelyn, Roseann, Aunt Pammy, Leah, Ted Wayne, Charlie Drucker, Jill, Barry, Chrissy, Clyde, John, Todd, Logan, Eddie and Judie Byrd, Julie Tamborino, Cole Aris, Emma Sanning, Julia Nesbitt, Mark Lipschitz, Cynthia Lipschitz, Wendi and Erik

And finally, to Grandi – my *fabulous* guardian angel. I love you a bushel and a peck.

ACKNOWLEDGMENTS

This dissertation would not have been possible without support and encouragement from an incredible community. First and foremost, all of my gratitude to my dissertation committee: Mardelle Shepley, Jane Mendle, and Anthony Burrow. When the idea for this dissertation was just a small seed, you provided the guidance and resources to nurture it into rigorous and high-impact research. What a joy it was to work with such an interdisciplinary, community-engaged committee for the past four years.

To Naomi Sachs – thank you for being an honorary member of my committee through your commitment to my development as a health design researcher (and my wellbeing as a PhD student). You left enormous shoes to fill.

Many thanks to the D+EA faculty – in particular, Gary Evans, Nancy Wells, and Lorraine Maxwell – whose scholarship and guidance informed my teaching interests, research directions, and future career in environmental psychology.

To the community partners who (literally) opened doors for me during site visits, assisted with participant recruitment, and selflessly extended their resources and networks to me:

- Brock Yetso, Maeve Koch, Sasha Nader, Christina Miller, Amanda Kesler, Samantha Horn, and many other navigators, survivors, and clinicians through the Ulman Foundation (formerly the Ulman Cancer Fund for Young Adults)
- Mallory Casperson (and her endless network of individuals within the AYA community) through Lacuna Loft

- David Victorson of True North Treks and Northwestern University
- Hilary Gan, Alexandra Kruis, and Simon Davies at Teen Cancer America
- Lamia Barakat and Etalia Johnson at the Children's Hopsital of Philadelphia
- Elena Wright and Karen Albritton through the Fort Worth AYA Oncology Coalition
- The SAMFund and First Descents network

Several funding agencies provided financial assistance for this research. Thank you to the Department of Design + Environmental Analysis and the Graduate School at Cornell University for providing dissertation grants. To Don Stabile and the St. Mary's College of Maryland Office of Alumni Relations – a huge thank-you to my alma mater for honoring me with your doctoral scholarship. A special thanks to the two design organizations who recognized the value of social science in health design: the Center for Health Design who honored me with the New Investigator Award, and the American Institute of Architects' Academy of Architecture for Health who awarded me the Arthur N. Tuttle Fellowship in Health Facility Planning and Design.

Finally, to my friends and family. They say, "it takes a village," and I have a truly special one:

- Mardelle Shepley and Naomi Sachs, for making sure my health and happiness always came first. And for proving the importance of powerful, brilliant female mentors in academia.
- Four cohorts of D+EA grad students, for all of the laughs, empathy, and curry on Fridays.

- My parents, for being the best cheerleaders from the sideline, the finish line, and the phone line.
- Eric May, my fiancé and soon-to-be-husband, for asking me to marry you in the middle of this chaos. You've proven what it means to be a partner.

TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

LIST OF ABBREVIATIONS

AYA(s)	Adolescent(s) and Young Adult(s)
AYAO	Adolescent and Young Adult Oncology
AYA HOPE	Adolescent and Young Adult Health Outcomes and Patient Experience
FGI	Facility Guidelines Institute
HIPAA	Health Insurance Portability and Accountability Act of 1996
HRQoL	Health-Related Quality of Life
JAYAO	Journal of Adolescent and Young Adult Oncology
PACI	Physical and Architectural Characteristics Inventory
PedsQL	Pediatric Quality of Life Inventory™
SEER	Surveillance, Epidemiology, and End Results Program
SEM	Social Ecological Model
SPS	Social Provisions Scale

CHAPTER 1 – INTRODUCTION

INTRODUCTION

Cancer is the number one disease-related cause of death in adolescence and young adulthood, with nearly 70,000 young people diagnosed with cancer in the United States each year. In 2012, four times the number of adolescents were diagnosed with cancer than children (Fidler et al, 2017). While adolescents and young adults are affected by different types of cancer than children and adults, they also have different psychosocial needs to fulfill. As such, a cancer diagnosis represents a unique and complex context for development. The ecological environment of cancer treatment during adolescence and young adulthood can impact the successful achievement of a number of developmental goals.

Though the age boundaries of adolescence in modern society are ambiguous, adolescence generally begins at puberty and ends with the transition to adult roles, marked by a myriad of biological, social, and psychological changes in between (Steinberg, 2017). Adolescence typically begins around age 10 and ends in the early 20s, though the bounds have extended in recent decades as puberty is beginning earlier and financial independence, career selection, and marriage are being achieved later.

This age period is no longer considered to be a time of "storm and stress," as suggested by G. Stanley Hall (196/4/19 1:14:00 PM04) when he defined adolescents by their tendency towards conflict, moodiness, and risky behavior. Rather, psychologists consider adolescence a time where youth are more susceptible to the negative effects of stress (Arnett, 1999), especially in the context of the environment in which their transitions are occurring. For adolescents faced with a cancer diagnosis,

both the stressors and the environment are unique and salient forces on development.

During the transition from late childhood to young adulthood, adolescents experience a number of biological, cognitive, and social changes – including physical growth, sexual maturation, greater risk-taking, and demonstrations of abstract thinking. These transitions support the achievement of unique psychosocial goals during adolescence. Adolescents experience five major developmental challenges – developing an identity, establishing autonomy, forming intimate relationships, expressing sexuality, and becoming a competent, successful member of society (Hill, 1983). The successful achievement of these psychosocial goals can vary widely due to the context in which the individual develops (Hill, 1983).

In 2006, the Adolescent and Young Adult Oncology Progress Review Group called researchers to "identify the characteristics that distinguish the unique cancer burden in the AYAO patient" (National Cancer Institute, 2006). This includes the developmental characteristics of adolescent patients, distinguished by the review group under six domains – intellectual, interpersonal, emotional, practical, existential/spiritual, and cultural. While the group recognized the influences of these developmental challenges on patient outcomes and quality of life, they called on researchers to better understand these relationships. Further in the report, members emphasize that effective support of AYA [adolescent and young adult] patients is impossible without an understanding of how cancer impacts an individual's "sense of self-identity, self-esteem, spiritual perspectives, body image, perception of their future possible life goals, distress levels, peer relationships [and] family dynamics." With such importance placed on anticipating the effects of cancer on psychosocial

development, it is necessary to understand both the typical developments of adolescence and how a cancer diagnosis acts on an adolescent at multiple levels of influence.

This introductory chapter will review existing research on the psychosocial effects of cancer during adolescence in young adulthood, prior to presenting findings from three doctoral studies answering the call to AYAO research. Though the broader dissertation addresses the role of the built environment for AYAs with cancer, the first step in a human-centered design process requires an understanding of a user population's unique circumstances (and the context in which those circumstances occur).

The Ecological Model

The context of development will be described using the ecological systems theory (Bronfenbrenner, 1977), which examines the relationship between an individual and their environment at multiple levels of influence across the lifespan. This section will address all four levels of the ecological model, with an emphasis on influences within the microsystem, or an individual's immediate environment. Applying the ecological model to adolescent development during cancer treatment allows both researchers and practitioners to understand the challenges inherent for adolescents with cancer. The model also provides a framework to improve cancer treatment for adolescents by ensuring the opportunities to explore identity.

In an effort to address the limitations of laboratory research in human development (namely those concerning generalizability), Urie Bronfenbrenner (1977) proposed the ecological model – a framework for contextualizing the environment

beyond an individual. Bronfenbrenner's original ecological environment is a bidirectional system of nested levels surrounding the individual. Each level is reciprocal, such that the environment acts on the individual while the individual can act on the environment. The model can accommodate the study of multiple contexts or relationships and interactions between levels. The ecological environment consists of four levels:

- The microsystem comprises an individual's immediate environments, including the physical features and activities of those settings, as well as an individual's roles and relationships in those settings.
- The mesosystem concerns the interactions among elements of the microsystem, including the connections between parents and teachers or school officials. In this way, researchers can consider the "joint impact" of multiple settings (Bronfenbrenner, 1977).
- The exosystem consists of the informal and formal social structures that impact an individual's environment, but in which an individual is not directly involved. These factors could include a parent's workplace, a child's neighborhood, or the public transit system. Each of these factors can determine the characteristics of social interaction – with whom, when, how, where.
- At the highest level of the ecological model are the ideologies or institutions that construct our culture and society. Studies investigating the macrosystem are often cross-cultural studies that examine an individual's social context but may also include interventions that dramatically change an institution's policies.

Bronfenbrenner's ecological model has been adapted specifically for health

applications as the social ecological model (SEM) of health promotion (McLeroy, Bibeau, Steckler, & Glanz, 1988). SEM has been used to evaluate the efficacy of health policy interventions, particularly with programs promoting physical activity or healthy food choice (Fleury & Lee, 2006; Gregson et al., 2001). The broader concepts of the micro-, meso-, exo-, and macrosystems were transformed into influences at the interpersonal, organization, community, and public policy levels, respectively.

SEM could be used as a tool for evaluating a specific health care intervention for adolescents with cancer. However, because the aim of this section is to frame the impact of cancer on adolescent psychosocial development, Bronfenbrenner's original ecological model is most appropriate as it was specifically proposed to address issues of human development.

The Psychosocial Impact of Cancer During Adolescence

Adolescence is the most common time for the first appearance of serious psychological difficulties (Kessler et al., 2005), making it an even more challenging experience when compounded with a cancer diagnosis – leading researchers to consider adolescence the "most demanding stage of life in which to be called upon to deal with cancer" (Gavaghan, 1984). Compared to their healthy counterparts, adolescents with cancer have demonstrated short- and long-term disruption in the five domains identified by Hill (1983) – identity, autonomy, intimacy, sexuality, and competence.

At a time when a healthy adolescent may be experiencing identity exploration and "trying on" many interests, appearances, and relationships, an adolescent with cancer is faced with the unique challenge of incorporating cancer into their existing

identity. Patients often report having to "renegotiate" their identity due to a lack of fit in their environment after treatment (Mathieson & Stam, 1995; Kumar & Shapira, 2012). The majority of adolescent survivors report a negative impact of cancer on their body image (Pendley, Dahlquist, & Dreyer, 1997; Bellizzi et al., 2012).

As a cancer diagnosis affects relationships with both caregivers and peers, adolescents with cancer experience difficulty developing autonomy and intimacy. Adolescent patients report a negative impact on relationships with both friends and romantic partners, with 1 in 4 patients reporting a disruption with a significant other (Bellizzi et al., 2012). After transitioning to a role as a patient, 25% of adolescents report having less confidence in their ability to take care of their health, and nearly 50% reported having less control over their life.

Expressing sexuality is a unique challenge for adolescents with cancer in part due to the isolating environment of cancer treatment and the dramatic physical changes resulting from treatment itself. A large number of adolescents become infertile as a result of treatment, with some treatment protocols resulting in the loss of fertility for nearly all men and over half of women (Byrne et al., 1987), leading to developmentally-atypical conversations about sex in terms of family planning and fertility preservation.

Adolescent patients report negative effects on their educational opportunities, relationships with significant others, and family planning (Bellizzi et al., 2012), suggesting some disruption in competence. During the course of cancer treatment, adolescents are often absent from school and extracurricular activities for extended periods of time, delaying the opportunities for academic, career, and social

achievement.

These examples were only a glimpse of the psychosocial impact of cancer during adolescence, highlighting a few issues within each of the five challenges. For the purpose of this section, I will focus on the ecological model as it applies more specifically to an adolescent's identity – the psychosocial outcome that has often been identified as *most* disrupted by cancer.

A cancer diagnosis changes both the physical and emotional identity of an adolescent, leading a sample of 83 adolescent cancer patients to rank "feelings about the appearance of your body" as the domain of greatest negative impact followed by "control over your life" (Bellizzi et al., 2012). While these reports may appear to be simply the hallmarks of adolescence (regardless of a cancer diagnosis), there is evidence that identity formation is a unique struggle for adolescents with cancer. Many adolescents with cancer experience hair loss, weight gain, scarring, skin discoloration, and/or amputations over the course of treatment. A significantly greater number of adolescent survivors are considered "identity foreclosed" – or having chosen an identity without exploration of other possibilities – compared to their healthy counterparts, perhaps as a coping mechanism (Madan-Swain, et al., 2000). Unique issues of identity extend even beyond the immediate impact of treatment, as survivors report having to reinvent themselves during the post-cancer transition (Cantrell & Conte, 2009). Given the magnitude of adolescents with cancer reporting issues of identity, this section will describe aspects of the environment that influence identity development.

Applying the Ecological Model to Adolescents with Cancer

By understanding *how* and *at which levels* cancer acts to influence an adolescent's identity, researchers and industry specialists can design targeted interventions to minimize the disruptive nature of cancer treatment. Figure 1.1 summarizes the particular factors associated with this population, a discussion about which follows.

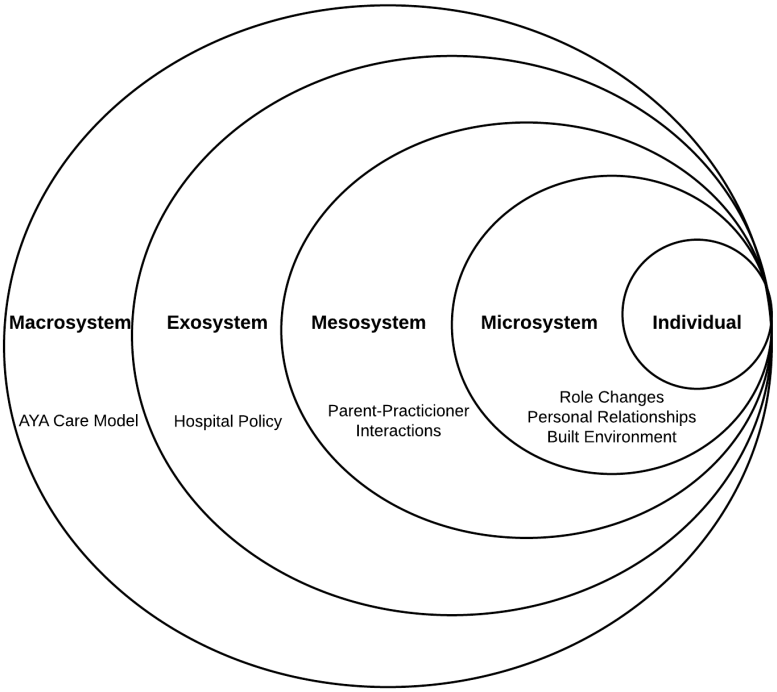


Figure 1.1. This diagram includes influences on identity development for adolescents with cancer at multiple levels of the ecological model (Bronfenbrenner, 1977).

Influences in the Microsystem

Adolescents spend most of their time in either the home or school microsystems. For adolescents with cancer, however, the microsystem expands to include the hospital and other clinical settings. The cancer treatment microsystem can

influence an adolescent's development in two ways: 1) Directly, as the features, roles, and relationships inherent to clinical settings act on the individual, and 2) Indirectly, as the transition from the home and school settings to a new setting influences development.

When an adolescent receives a cancer diagnosis and begins treatment, there is a role transition, such that an adolescent who has started to explore independence within his home and school microsystems is now a dependent patient in the hospital microsystem. Adolescents with cancer have reported more maternal conflict than their healthy counterparts, in part due to the adolescent's desire for independence and the mother's increased desire for protection during treatment (Manne & Miller, 1998). These role changes similarly influence identity development, as an individual's interactions with family members (including interactions related to autonomy) are correlated with identity exploration (Grotevant & Cooper, 1985).

Just as family relationships change after a cancer diagnosis, so do peer relationships. Peers now include two distinct groups: healthy peers and peers with cancer. This has been referred to as the "identity paradox" for cancer patients (Jones, Parker-Raley, & Barczyk, 2011). Identity development is tied directly to an adolescent's social group, and adolescents with cancer must grapple with the aspects of identity that are unique to each group. Adolescents report that peers with cancer can understand them in different ways than their healthy peers and often form new friendships, while simultaneously feeling isolated from previous groups and missing out on shared life experiences (Zebrack & Isaacson, 2012).

When an adolescent is removed from the school setting and spending a greater

amount of time in the hospital and home settings, not only do peer and family relationships change, but there is less opportunity afforded by the built environment for social interaction. Identity formation in adolescence depends on social interaction with peers and family members, but clinical spaces for immune-compromised patients are often prohibitive of social interaction.

Because the ecological model is bidirectional, a patient is being influenced by factors within the microsystem, while those environmental factors are reacting to the patient and their new health challenges. In the case of the built environment, the clinical setting should be adaptive and supportive to account for many different states of the patient.

Influences in the Mesosystem

While future research and interventions (including this doctoral research) will focus on addressing influences in microsystem, as they are most easily controlled by researchers, practitioners, and other decision makers, it is important to note influences of the meso-, exo-, and macrosystems.

For young people with cancer, the interactions between family members and health care providers in the mesosystem can impact development. Similar to the role transition experienced by an adolescent patient, a patient's parents (or the family caregivers) often find themselves adapting to roles as secondary caregivers. The nature of practitioner-parent relationships can influence the triadic practitioner-parent-patient relationship, which determines the information provided to the adolescent and the role that the patient has in their own care decisions (Tates, Elbers, Meeuwesen, & Bensing, 2002). Even the presence of parents at care meetings can affect the effectiveness of

communication and information provided between adolescents and doctors (Beresford & Sloper, 2003). Developing the capacity to advocate for personal wants and needs is often a marker of identity formation and autonomy in parent-child relationships but can also be observed in these clinical relationships.

Influences in the Exosystem

For an adolescent, influences in the exosystem may include changes at a parent's workplace or new school policies. While being treated for cancer, the exosystem includes the hospital policies and the larger operations of the national health care system.

One of the greatest barriers to identity development in the exosystem is the infection control policies inherent in any clinical setting, but most strongly enforced for immune-compromised oncology patients. Patients are often on precautions that preclude their participation in hospital-wide activities, impair their ability to visit with friends or family (particularly during flu season), and sometimes isolate them entirely, as occurs with patients who receive bone marrow transplants. Without the ability to connect with peers, family members, or mentors with whom to "try on" different identities, adolescents with cancer report greater incidence of identity foreclosure than their healthy peers (Cantrell & Conte, 2009).

Influences in the Macrosystem

The largest influence in the macrosystem (with arguably the greatest impact of any factor in a patient's ecological environment) is the "blueprint" for adolescent cancer treatment and its influence on patients. In many instances within the healthcare domain, the boundaries of adolescence do not line up with the boundaries proposed in

developmental psychology. Most facilities and agencies, including the National Cancer Institute, discuss “AYA” (adolescent and young adult) cancer programs, proposing an extended age period bound by ages 15 to 39. In human development literature, the biological, cognitive, and social differences between 15-year-old adolescents and 39-year-old adults are extensive. As such, boundaries this large are rarely ever used for the purpose of human development research on adolescents or young adults.

The Adolescent and Young Adult Health Outcomes and Patient Experience (AYA HOPE) Study, a survey of over 500 patients diagnosed between ages 15 to 39, revealed the extent of this issue. Researchers subdivided responses into three groups: ages 15-20, 21-29, and 30-39. While there were similarities across all age groups, there were also notable significant differences in the types of negative outcomes reported between the age groups, including a greater negative impact on educational plans but a weaker impact on sexual function and intimacy for the youngest cohort (Bellizzi et al., 2012).

To best treat the unique needs of a developing adolescent, hospitals and other treatment facilities must consider moving away from grouping adolescents and young adults together. A more proper division is now being used semantically by the National Cancer Institute, creating a distinction between young AYAs (ages 15 to 24) and older AYAs (ages 25 to 39), but this division still spans multiple life-stages. In 2013, the AYA Oncology Progress Research Group recommended continued use of ages 15 to 39 to define the AYA population, while conceding that it may be flexibly applied, specifically mentioning developmentally based definitions as more

appropriate in the psychosocial domain (Smith et al., 2016). There are multiple reasons for the continued use of the AYA health model, including the biological similarities within this age group that allow for similar treatment protocols within one facility. This does not preclude the possibility that adolescents and young adults could be provided with distinct spaces – within a single facility, distinctions could be made through the addition of developmentally-appropriate lounge spaces or room assignments based on age cohorts.

To receive the Center for Excellence award designated to AYA cancer facilities, a facility must provide (among other qualifications) psychosocial support for its patients (Health Care Rights Initiative, n.d.). This qualification, however, only requires that a center must establish several formal support services and provide certain resources – it makes no mention of the facility design that may critically support the efficacy of these resources. In meetings of the AYA Oncology Progress Review Group in 2006 and 2013, researchers and practitioners alike noted the importance of understanding the unique burden of cancer on adolescents, as well as the importance of providing developmentally-oriented care (Adolescent and Young Adult Oncology Progress Review Group, 2006; Smith et al., 2016). Like the Center for Excellence standards, however, there is no mention of the built environment.

Research Approach

Given the psychosocial disruption caused by cancer during adolescence and young adulthood coupled with the lack of evidence on the built environment, this dissertation will be significant in its ability to provide novel evidence-based guidelines for AYA cancer facilities. To arrive at those design guidelines, this dissertation takes a

three-part approach to explore the characteristics of AYA cancer, examine the adequacy of the current built environment, and include AYAs in a participatory design process. The following chapters comprise three studies (see Figure 1.2):

1. A set of semi-structured interviews with 15 participants treated for cancer between the ages of 15-39. These interviews informed a phenomenology of cancer during adolescence and young adulthood, classifying the impact of cancer into four themes and illuminating the unmet needs experienced by AYAs.
2. A patient questionnaire to evaluate the relationship between the built environment, quality of life, and social support, completed by 104 participants treated for cancer between the ages of 15-39. The results of this questionnaire revealed the inadequacies of the built environment and the role of certain environmental characteristics in the provision of social support.
3. Three participatory design focus groups with 15 AYA participants to discuss findings from the questionnaire and arrive at concrete recommendations for the built environment. These focus groups explore the use of a novel platform to engage participants in a virtual participatory design process, including group interviews and photo-sorting activities.

The following chapters describe the background, methods, and results of each study, concluding in the last chapter with a set of evidence-based design guidelines prepared for practitioners.

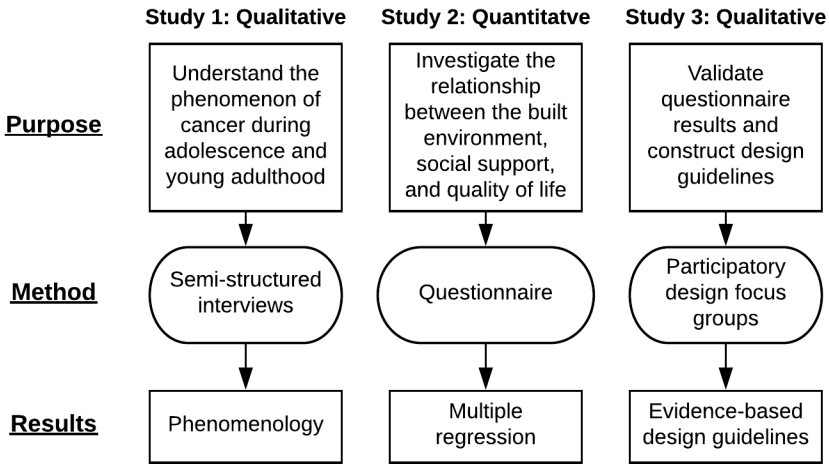


Figure 1.2. A diagram illustrating the three studies included in the doctoral dissertation, including the current study.

References

Adolescent and Young Adult Oncology Progress Review Group. (2006). *Closing the gap: Research and care imperatives for adolescents and young adults with cancer* (NIH Publication No. 06-6067). Bethesda, MD: National Cancer Institute, National Institutes of Health, and the LIVESTRONG Young Adult Alliance. Retrieved from https://www.cancer.gov/types/aya/research/ayao-august-2006.pdf

Arnett, J. J. (1999). Adolescent storm and stress, reconsidered. *American Psychologist*, 10.

Bellizzi, K. M., Smith, A., Schmidt, S., Keegan, T. H. M., Zebrack, B., Lynch, C. F., … and the Adolescent and Young Adult Health Outcomes and Patient Experience (AYA HOPE) Study Collaborative Group. (2012). Positive and negative psychosocial impact of being diagnosed with cancer as an adolescent or young adult. *Cancer*, *118*(20), 5155–5162. https://doi.org/10.1002/cncr.27512

Beresford, B. A., & Sloper, P. (2003). Chronically ill adolescents' experiences of communicating with doctors: A qualitative study. *Journal of Adolescent Health*, *33*(3), 172–179. https://doi.org/10.1016/S1054-139X(03)00047-8

Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American Psychologist*, *32*(7), 513–531. https://doi.org/10.1037//0003-066x.32.7.513

Byrne, J., Mulvihill, J. J., Myers, M. H., Connelly, R. R., Naughton, M. D., Krauss, M. R., … Strong, L. C. (1987). Effects of treatment on fertility in long-term

survivors of childhood or adolescent cancer. *New England Journal of Medicine*, *317*(21), 1315–1321. https://doi.org/10.1056/NEJM198711193172104

Cantrell, M. A., & Conte, T. M. (2009). Between being cured and being healed: The paradox of childhood cancer survivorship. *Qualitative Health Research*, *19*(3), 312–322. https://doi.org/10.1177/1049732308330467

Fleury, J., & Lee, S. M. (2006). The social ecological model and physical activity in African American women. *American Journal of Community Psychology*, *37*(1–2), 141–154. https://doi.org/10.1007/s10464-005-9002-7

Fidler, M. M., Gupta, S., Soerjomataram, I., Ferlay, J., Steliarova-Foucher, E., & Bray, F. (2017). Cancer incidence and mortality among young adults aged 20–39 years worldwide in 2012: a population-based study. *The Lancet Oncology*, *18*(12), 1579–1589. https://doi.org/10.1016/S1470-2045(17)30677-0

Gavaghan, M. P. (1984). *Psychosocial Development of Adolescents with Cancer: Identity, Locus of Control, Patient Compliance* (Dissertation). The Ohio State University, Ann Arbor. Retrieved from https://search.proquest.com/docview/303300507?accountid=10267

Gregson, J., Foerster, S. B., Orr, R., Jones, L., Benedict, J., Clarke, B., … Zotz, K. (2001). System, environmental, and policy changes: Using the social-ecological model as a framework for evaluating nutrition education and social marketing programs with low-income audiences. *Journal of Nutrition Education*, *33*, S4–S15.

Grotevant, H. D., & Cooper, C. R. (1985). Patterns of interaction in family

relationships and the development of identity exploration in adolescence. *Child Development*, *56*(2), 415. https://doi.org/10.2307/1129730

Hall, G. S. (1904). *Adolescence* (Vols. 1 & 2). New York: Appleton.

Health Care Rights Initiative (HCRI). (n.d.). Change it Back: Centers of Excellence Program. Retrieved March 21, 2017, from http://hcri.org/programs/change-it-back/

Hill, J. P. (1983). Early adolescence: A research agenda. *The Journal of Early Adolescence*, *3*(1–2), 1–21. https://doi.org/10.1177/027243168331002

Jones, B. L., Parker-Raley, J., & Barczyk, A. (2011). Adolescent cancer survivors: Identity paradox and the need to belong. *Qualitative Health Research*, *21*(8), 1033–1040.

Kessler, R. C., Berglund, P., Demler, O., Jin, R., Merikangas, K. R., & Walters, E. E. (2005). Lifetime prevalence and age-of-onset distributions of DSM-IV disorders in the National Comorbidity Survey replication. *Archives of General Psychiatry*, *62*(6), 593–602. https://doi.org/10.1001/archpsyc.62.6.593

Madan-Swain, A., Brown, R. T., Foster, M. A., Vega, R., Byars, K., Rodenberger, W., … Lambert, R. (2000). Identity in adolescent survivors of childhood cancer. *Journal of Pediatric Psychology*, *25*(2), 105–115.

Manne, S., & Miller, D. (1998). Social support, social conflict, and adjustment among adolescents with cancer. *Journal of Pediatric Psychology*, *23*(2), 121–130.

Mathieson, C. M., & Stam, H. J. (1995). Renegotiating identity: Cancer narratives. *Sociology of Health & Illness*, *17*(3), 283–306.

McLeroy, K. R., Bibeau, D., Steckler, A., & Glanz, K. (1988). An ecological

perspective on health promotion programs. *Health Education Quarterly*, *15*(4), 351–377.

Pendley, J. S., Dahlquist, L. M., & Dreyer, Z. (1997). Body image and psychosocial adjustment in adolescent cancer survivors. *Journal of Pediatric Psychology*, *22*(1), 29–43.

Smith, A. W., Seibel, N. L., Lewis, D. R., Albritton, K. H., Blair, D. F., Blanke, C. D., … Zebrack, B. J. (2016). Next steps for adolescent and young adult oncology workshop: An update on progress and recommendations for the future. *Cancer*, *122*(7), 988–999. https://doi.org/10.1002/cncr.29870

Steinberg, L. D. (2017). *Adolescence*. New York: McGraw-Hill.

Tates, K., Elbers, E., Meeuwesen, L., & Bensing, J. (2002). Doctor–parent–child relationships: A 'pas de trois.' *Patient Education and Counseling*, *48*(1), 5–14. https://doi.org/10.1016/S0738-3991(02)00093-9

Zebrack, B., & Isaacson, S. (2012). Psychosocial care of adolescent and young adult patients with cancer and survivors. *Journal of Clinical Oncology*, *30*(11), 1221–1226. https://doi.org/10.1200/JCO.2011.39.5467

CHAPTER 2 – INTERVIEWS

CANCER DURING ADOLESCENCE AND YOUNG ADULTHOOD: A PHENOMENOLOGICAL EXPLORATION OF UNMET NEEDS THROUGH INTERVIEWS WITH AYA SURVIVORS

Adolescents and young adults with cancer (AYA) have been studied in recent years to understand their unmet needs and the developmental hardships resulting from their illness. Though these studies reveal a great deal about different facets of cancer care (and identify areas for improvement), they fail to provide a holistic view of the *experience* of cancer as a young person. As a method of inquiry in qualitative research, phenomenological research is designed to explore the "overall essence of the experience" (Creswell, 2007) and is the first step to understanding the unique hardships and responsibilities facing young people during cancer treatment. These interviews inform future research in AYA cancer environments by describing the phenomenon of cancer during adolescence or young adulthood. Through semi-structured interviews with former patients, the phenomenon is viewed from multiple angles to create both textural and structural descriptions of cancer during adolescence.

Phenomenology did not begin as a qualitative research methodology, but rather has its roots in traditional philosophy. As a German philosopher in the late 1800s, Edmund Husserl presented phenomenology as an opportunity to explore the "essence" of human experience through intentional, directed consciousness and the reservation of any pre-conceived notions about the experience (Moran, 2000). Phenomenology has developed as a philosophy since Husserl but many of the basic principles remain. Fochtman's (2008) description of phenomenology is an excellent resource for both

health science researchers and clinicians unfamiliar with the field. Because it has been documented at length, I will focus less on the philosophical foundation of phenomenology and more on its adaptation as a research methodology.

Researchers have used these phenomenological methods to explore a number of patient experiences in cancer, including fatigue (Potter, 2004; Ream & Richardson, 1997), receiving the bad news of a cancer diagnosis (Stegenga & Ward-Smith, 2009; Tobin & Begley, 2008), breast cancer survivorship (Thibodeau & MacRae, 1997), and siblings' experiences (Woodgate, 2006) – among many others. One of the more comprehensive examples in the cancer literature, Fochtman's (2010) phenomenology of cancer in adolescence provides a composite description of the experiences of seven adolescents (aged 14 to 18). Her description comprises seven themes, including support, resilience, and spirituality. In some individual descriptions, participants mention the influence of the environment or the outdoors, but it was not probed for further exploration. The current study seeks to expand on Fochtman's approach by encouraging participants to describe their experience with cancer in the context of place. It will also include perspectives from those with cancer during adolescence *and* young adulthood, aligning with the National Cancer Institute's grouping of adolescents and young adults as the AYA cohort – from ages 15 – 39.

Methods

When creating a phenomenology, researchers typically have two approaches from which to choose: Martin Heidegger's hermeneutical phenomenology (van Manen, 1990, 2016) or Husserl's transcendental phenomenology (also called psychological phenomenology) (Moustakas, 1994). Both approaches seek to explain

the human experience but emphasize different methodology. Hermeneutical phenomenology relies on "reflexive interpretation" of a primary source – most often used for inquiries in history and art. Alternatively, transcendentalists collect data and follow a prescribed analytical process to understand meaning (Moerer-Urdahl & Creswell, 2004). Transcendental phenomenology is more frequently used for empirical work in the social sciences. Moustakas' method (1994) is most commonly used to collect analyze data in a phenomenological study with a transcendental approach – the approach that is best suited for the data collected in this study. The following is a summary of Moustakas' phenomenological method (1994):

1. Prepare to Collect Data
    a. Formulate the question
    b. Conduct literature review and determine original nature of study
    c. Develop criteria for selecting participants
    d. Develop instructions and guiding questions or topics needed for the interview
2. Collecting Data
    a. Engage in the Epoche process as a way of creating an atmosphere and rapport for conducting the interview
    b. Bracket the question
    c. Conduct the qualitative research interview to obtain descriptions of the experience.
3. Organizing, Analyzing, and Synthesizing Data
    a. Follow modified van Kaam method or Stevick-Colaizzi-Keen method
    b. Develop individual textual and structural descriptions; composite textural and composite structural descriptions, and a synthesis of textural and structural meanings and essences of the experience
4. Summary, Implications, and Outcomes
    a. Summarize entire study
    b. Relate study findings to and differentiate from findings of literature review
    c. Relate study to possible future research and develop an outline for a future study
    d. Relate study to personal outcomes
    e. Relate study to professional outcomes
    f. Relate study to social meanings and relevance
    g. Offer closing comments

Sample and Recruitment

Semi-structured interviews were conducted sixteen participants – one of whom was participating as a pilot interviewee and for whom data is not included. The fifteen other participants were between the ages of 20 – 39 and had previously been treated for cancer as an adolescent or young adult. The fifteen interviewees varied in age, diagnosis, and duration of treatment (see Table 2.1). Participants were excluded if their treatment concluded prior to age 15. Approval for exemption was obtained from the Institutional Review Board at Cornell University. These participants were recruited through social media postings in a Facebook group for the Ulman Cancer Fund for Young Adults (Baltimore, MD), outreach through other AYA-oriented organizations, and word-of-mouth. Participants names have been changed. I have also redacted references to other specific people or facilities that may identify a participant.

Table 2.1

Participant Profiles by Demographic

Participant	*Gender*	*Age at interview*	*Age at first diagnosis*	*Age when treatments completed*	*Type of cancer*
1	Female	24	16	19	Cervical (unspecified)
2	Female	20	18	19	Hodgkin's lymphoma
3	Male	20	19	21	Hodgkin's lymphoma
4	Male	29	23	23	Leukemia
5	Female	26	17	18	Hodgkin's lymphoma
6	Female	36	30	31	Breast (unspecified)
7	Female	39	36	37	Breast (unspecified)
8	Female	38	35	35	Breast (unspecified)
9	Male	35	31	31	Brain (unspecified)
10	Female	36	25	25	Hodgkin's lymphoma
11	Male	27	25	25	Testicular (nonseminoma)
13	Female	35	33	34	Cervical (unspecified)
14	Male	35	26	26	Testicular (unspecified)
15	Female	24	17	23	Non-Hodgkin's lymphoma

Interview Methods

Though the interview questions varied depending on the participant's experience (particularly those who received bone marrow transplants) and some participants were probed with follow-up questions or requests for specification, the interviews broadly addressed the following topics:

- The experience of cancer during adolescence or young adulthood
- Hardships facing adolescents and young adults with cancer
- Unmet needs (both emotional and physical) for AYAs

- Social behavior in a healthcare setting
- Preferences in the physical healthcare environment

  Interviews were conducted between July 2017 and May 2018. Interviews mainly took place remotely via phone and were recorded with TapeACall Pro. Early interviews were transcribed using an independent transcription service (and revised where necessary). In the later stages of the study, interviews were transcribed personally by the investigator using Trint, a transcription software. Interviews were transcribed verbatim – an important characteristic of the Stevick-Colaizzi-Keen method (detailed below). Interview transcripts and written notes were imported into Atlas.ti for qualitative analysis.

Analytical Methods

Just as there is a lack of consensus regarding the appropriate orientation for phenomenological research, there is equally little agreement regarding the appropriate steps for data analysis. Colaizzi's (1978) steps for phenomenological data analysis are frequently used in nursing research to evaluate narrative patient data and are still considered successful in creating a thorough description of health phenomena (Shosha, 2012). Moustakas (1994) recommends a modified version of Colaizzi's method, commonly known as the Modified Stevick-Colaizzi-Keen method. The following are the seven steps in the Stevick-Colaizzi-Keen phenomenological method, as simplified and recommended by Creswell (2007):

1. First describe personal experiences with the phenomenon under study. The researcher begins with a full description of his or her own experience of the phenomenon. This is an attempt to set aside the researcher's personal experiences (which cannot be done entirely) so that the focus can be directed to the participants in the study.

2. Develop a list of significant statements. The researcher then finds statements (in the interviews or other data sources) about how individuals are experiencing the topic, lists these significant statements (horizontalization of the data) and treats each statement as having equal worth, and works to develop a list of nonrepetitive, nonoverlapping statements.

3. Take the significant statements and group them into larger units of information, called "meaning units," or themes.

4. Write a description of "what" the participants in the study experienced with the phenomenon. This is called a "textural description" of the experience – what happened – and includes verbatim examples.

5. Next write a description of "how" the experience happened. This is called "structural description," and the inquirer reflects on the setting and context in which the phenomenon was experienced.

6. Finally, write a composite description of the phenomenon incorporating both the textural and structural descriptions. This passage is the "essence" of the experience and represents the culminating aspect of a phenomenological study. It is typically a long paragraph that tells that reader "what" the participants experienced with the phenomenon and "how" the experienced it (i.e., the context).

Epoche

Moustakas' first step is the "Epoche" process – setting aside any biases, preconceived notions, or personal experiences. Achieving Epoche allows researchers to focus solely on the information provided by the participants. Bracketing personal experiences entirely is impossible, but Moustakas encourages researchers to conscientiously document their attempts.

During the Epoche process, Moustakas suggests that the researcher approach with openness "whatever and whoever appears in our consciousness, seeing just what is there and allowing what is there to linger." He encourages researchers to be transparent with themselves and refrain from taking any positions in advance.

My personal experience with AYA cancer began during my own adolescent years with the diagnosis of my aunt with genetic breast cancer in her 30s, at which time I elected to undergo testing for the BRCA mutation. I recall several weeks of intense worry while I awaited the results. I contemplate now the anxiety that these tests evoked for me and my family, as well as the relief when the test came back negative. I recall the experience of volunteering with the Ulman Cancer Fund for Young Adults, during which I read a great deal of material on AYA cancer and interacted with many patients. I felt that many patients did not have access to the right care or spaces for treatment. I reflect on these memories and set them aside.

I acknowledge my preconceived notion that the built environment can influence health and social interactions. Though this hypothesis is central to my thesis work, I attempt to disconnect myself from this theory for the extent of the interviews and analyses.

Most notably, I am a young adult at the time of writing and recently diagnosed with a chronic illness. This illness comes to mind as I think about the cancer experience and how activities and goals can be disrupted by symptoms and treatment, especially the goals of adolescence and young adulthood. I acknowledge this hypothesis as well, setting it aside to learn more fully from the participants.

Significant Statements and Meanings

After reading through the transcripts and notes from each interview, I used Atlas.ti to highlight significant statements from each interview. The interviews resulted in an average of 33 significant statements per participant. Significant statements are usually sentences or short quotes (Creswell, 2007), like the following

statement from one participant:

> I had an apartment to study abroad in Barcelona, Spain that semester in the fall. And instead I went to lovely [redacted] to get a bone marrow transplant. It was kind of a 180 from my dream to dealing with cancer treatments and hospitals and stuff.

Themes

Four themes emerged within the significant statements after meanings were identified. For example, statements coded with "seeking information" and "providing information" both clustered under a similar concept – "AYAs are information seekers and providers." I chose to describe the themes as *identities* that an AYA may adopt during the course of their cancer journey. The concept of identity is integral to adolescent and young adult development; thus, these themes represent the shifts in identity described by participants.

AYAs as a Distinct Group

Participants described feelings of uniqueness in this period of development. They are not children or adults and have distinct needs as a cohort. Many participants struggled with feeling older than a typical pediatric patient – one male participant mentioned a "lack of clarity as to why a teenager would be treated at a pediatric hospital." Other participants often referred to the ways in which adolescent patients differ from pediatric patients, suggesting that adolescents are much more social and have the ability to conceptualize their own mortality in ways that a younger patient cannot. One female participant recalled "As a teenager, one of the things that is so difficult about going through treatment is that you have a full conception of what is

going on and it's very scary and you feel like all the power has been taken away from you." Another female participant mentioned social differences as well, saying "AYAs are a very social group of people versus the kids and the geriatric patients. Children don't really have the capacity to be social and geriatric patients don't necessarily want to be." Participants used comparison words frequently to describe AYAs and other cohorts.

One female participant talked about the "hallmarks of being an adolescent" – fitting in, making social connections. Another participant elaborated on this idea, saying "In high school you're so aware and nervous about your appearance or being the sick kid or sticking out or being a weirdo in class so I think that is a lot of pressure on people especially when they're developing." A female participant mentioned the "big milestones that you hit in the AYA time period," like transitioning from high school to college or single to married. She suggests that "when you're working with kids or you're working with geriatric patients, they don't have those really big transitions, so you don't have to worry about it." Other participants also discussed the body image challenges unique to AYAs, saying "As a teenager you probably just don't feel comfortable with your body anyway, but as a teenager going through chemo, you're in an uncomfortable state with your body." When talking about wigs, one female participant said "the looks and strategies that work for older women might not necessarily work for younger patients, because younger patients are typically more active than older people going through chemo. [AYAs] still try and maintain a social relationship with their friends and do activities which are less cohesive to wigs and stuff." A male participant said something similar, "A lot of the older people obviously

aren't as active as younger people."

AYAs as Information Seekers and Providers

All participants described times in which they felt under-informed. A male participant mentioned the that some facilities "struggle to let the adolescent and young adult patients know why they're being treated in a pediatric hospital." He also found his second round of treatment more bearable because "I knew what to expect, I knew how to eat, I knew how to prepare my body, which wasn't clear to me the first time." He said the first round of treatment came with a lot of unknowns that I had to just learn for myself, but I don't think that there was a reason that I had to learn them for myself." Another male participant reported that he was "constantly asking 'What does this medicine do?' or 'How much is this?' and asking questions of everything that goes on."

Nearly every participant reported they were not aware of many support groups until after finishing treatment. One female participant wished for "some system to facilitate those connections with somebody who is of your age and can also communicate these things to you." Many participants described their relationships with social workers, often positively, as they were a source of information and advocacy during difficult periods of treatment.

One female participant said "I think that AYAs are really good advocates for themselves once given the platform. I think AYAs really need someone to ask them what they think and then they'll give a billion ideas." Another participant echoed this, saying "Giving patients the agency to make those decisions for themselves was a very important thing."

Although participants reported a lack of information from staff and outside organizations, they frequently shared information with their peers. Many participants continue to stay heavily involved in the AYA cancer community. This might be because, as one participant suggested, "It's like the teenage thing… you just want to be heard."

One male participant recalled his own experience as a first-time transplant patient – "You're really scared. And all this stuff is happening, and you don't know what to expect." Although no one did it for him, he often volunteers to speak to young people who have been recently diagnosed. He says "I'm very good about giving it to the people like real, like yeah this is going to suck. Like you're not going to want to do this again after you're done… but look, I'm still here…so don't worry about that part."

One participant took his experience and translated it into a Master's thesis on healing spaces. Several participants work for a non-profit cancer organization. Still other serve as ambassadors for their respective cancer organizations and raise money annually for the cause.

AYAs as Transitioners

Adolescence and young adulthood are a time of great transition for healthy young people. As one participant mentioned, "when you're working with kids or you're working with geriatric patients, they don't have those really big transitions, so you don't have to worry about it." Participants reported more than just typical developmental transitions, however. One female participant mentioned how her goals changed dramatically after cancer, saying "When you're in treatment you have the

goal to get healthy...And then once you're out of treatment you have much less serious goals, like graduating." One male participant's trajectory changed too. He said "Five years I had an apartment to study abroad in Barcelona, Spain that semester in the fall. And instead I went to lovely [redacted] to get a bone marrow transplant. It was kind of a 180 from my dream to dealing with cancer treatments and hospitals and stuff."

When discussing his experience, this male participant mentioned ways that he tried to take advantage of his time in treatment and make it positive, setting new goals. He said, "I want to learn as much as I can, and I have six months to literally sit here and do whatever I want." He read books, listened to music, and watched movies. Another male participant said something similar, "I took up poker pretty seriously. I played a lot of online poker and I started studying it really hard and I got pretty good and I also, I read a lot of book or like listened to a lot of audio books."

Even though AYAs are returning to the same "outside world," their experience in the outside world is different. When one female participant returned to school, she repeated courses with the same professors and returned to the same dorm. She recalled "Even though that environment was completely the same, the person inside the environment is completely different… Like that's a past Amy [name changed]."

AYAs as Outsiders

This theme encompasses both a lack of fit in the physical environment and the more abstract social environment, as situated within Bronfenbrenner's ecological model in Chapter 1.

Though the participants categorize themselves as separate from pediatrics and adults (Theme 1), many participants mentioned that this hasn't translated to medical

terminology. A female participant said, “People don’t even know who AYAs are.” She mentioned that even very large non-profits had never heard of the AYA age group. This was surprising to her – “the fact that they didn’t recognize the term kind of implies that they didn’t really know about the population.” Another participant put it succinctly, “It’s isolating. It’s a very isolating situation.” Later in the interview she reiterated this, saying “It’s a very lonely and isolating period of life at a time when as a teenager you just want to fit in and get along.” She referred to her isolating experience as the “treatment box.” A male participant described himself as “bubble boy.”

One male participant discussed his decision to take full-time credits while in treatment and compared himself to his healthy peers, saying “I wanted to graduate on time just like everyone else.” A female participant said, “It’s kind of salt in the wounds sometimes where you’re seeing your peers go on and live these lives and you can viscerally see that you’re getting left behind.”

When describing how she really wanted social interaction, one participant recalls feeling like she was the “only person that had cancer at 16.” Another participant said, “One of the hallmarks of my experience going through chemo…is that you don’t really connect with many people and it exacerbates that feeling of loneliness and rejection and isolation during that time.” All participants reported that they would text or call their friends at home but didn’t have the energy or self-confidence to see very many people in-person. Many participants reflected on times when they had been put in touch with former patients, but it was less helpful because those contacts were not their age. A male participant mentioned that the volunteer in

his hospital was an older retired person. A female participant said "I was offered contacts of former pediatric patients who were in their thirties at the time. So, they were recommending that I reach out to them, kind of hear these survival stories and stories of encouragement, but those weren't the voices at that times that I wanted or needed to hear."

In the physical environment, participants reported similar feelings. Many participants described dissatisfaction with their treatment facilities. A male participant said his facility was "way too heavy with the child games and children-centric stuff, like art therapy and always playing Disney Channel and like the dolls and stuff." He mentioned that when he began treatment, there was "no place for teenagers, AYAs or even young kids who just like weren't into that stuff to like be separate. They just sort of had to sit there listening to like all this like high pitch speaking." One female participant mentioned cartoons too, saying "Everything was colorful, and they constantly had Disney Channel playing in the background." Another participant reiterated this, saying "There were a couple community room type things, but a lot of that was not used for patients because there were always kids in there."

Many participants felt like their treatment spaces weren't designed with patients in mind. Like many cancer patients, one male participant described having to carry an IV pole, but with brick and paving on some walkways, he was susceptible to having his IV pole fall over and rip out. Another participant had a similar experience, suggesting that it's difficult when designers aren't in touch with AYAs – she said "For some reason everyone thinks that adolescents and young adults want a pool table and video games. It never turns out to be productive because the people who are putting in the

video games or the pool table – they weren't AYAs, they weren't in that age."

Textural Description – The "What"

After evaluating meanings and grouping those meanings into themes, phenomenological researchers condense these themes into an exhaustive textural description of the experience. Exhaustive is not to mean that the description itself is lengthy (though it can be) but rather that it incorporates all themes into a full narrative of the experience – one that will ultimately be narrowed down into its core parts when synthesized with the structural description to form the composite description. The textural description describes the "what" of AYA cancer, while the structural description describes the "how" or the context.

Adolescents and young adults (AYAs) with cancer are unique from their pediatric and adult counterparts. They are experiencing a developmental transition in goals, needs, and desires that is disrupted (in some cases, redirected) by cancer treatment. In their efforts to navigate through cancer treatment, AYAs seek information about their conditions and desire agency in their treatment plans but may not receive it. Drawing from personal experience (for those who receive multiple rounds of treatment) and peer experiences (for those who are newly diagnosed or anticipating a new procedure) can alleviate feelings of anxiety.

When AYAs complete treatment and enter into survivorship, they are challenged to return to their previous routines and often experience negative consequences. Positively, however, many AYAs contribute to the cancer community during survivorship, often lending their own narratives to their

peers in treatment (recognizing the lack of information available to the AYA cohort).

Structural Description – The "How"

The structural description describes the context in which the participants experienced cancer as young people. Notably, the place in which participants were treated was influential in how participants experienced cancer. Positive distraction plays an important moderating role in the treatment process, but often isn't afforded by the environment. AYAs are often treated in a pediatric setting, where opportunities for recreation, access to nature, entertainment materials, and other sources of positive distraction are either not available or age-appropriate.

Participants also noted their peers (or lack thereof) as an important element. Participants reported a desire for peer social interaction but difficulty connecting to other young people, due to a host of issues including mobility constraints, body image concerns, lack of other young people in the facility, HIPAA regulations, reluctance to join support groups, and a disinterest in talking about cancer. Healthy friends, family, social workers, and clinical staff provide other avenues of social support, though the isolating and debilitating nature of most treatments is a barrier to social interaction.

Discussion

Achieving epoche (or bracketing personal experience from a study) is a challenge that is not unique to phenomenological research, but it must be carefully addressed when creating descriptive conclusions. As a young adult at the time of this

paper, I acknowledge that my lived experiences somewhat overlap with the phenomenon even though I have not directly experienced cancer. Several themes that emerged from this research were not unlike some of the challenges faced by healthy adolescents and young adults in the course of development, though certainly magnified and intensified when coupled with cancer.

As van Manen (1990) suggests, one phenomenological description is not an exhaustive description of the human experience, but rather a single interpretation among many possible interpretations. While I believe my interpretation has practical merit for clinicians and future researchers, a philosophical phenomenologist may take issue with the mono-method approach of simply interviewing participants (a phenomenology can also be created through observations, analysis of written work, or the evaluation of artwork).

For similar reasons, some phenomenologists have taken to critically referring to phenomenological research in health sciences as "new phenomenology" (Crotty, 1996, as cited in Barkway, 2001). I believe there is a legitimate place in applied social science research for phenomenological description, even as it diverges from the original philosophical intent. A rich description of the human experience is a requirement for human-centered design.

With the value of phenomenological research still debated, Munhall (2007) urges researchers to demonstrate the significance of their work by recommending implications for change based on their interpretations. The experience described in this phenomenology is not novel – AYA patients have reported unmet needs across a number of previous studies, including several large-scale population surveys (Keegan

et al., 2012; Smith et al., 2013). However, understanding more fully the factors that influence the achievement of these needs (peers, facility design, etc.) allows administrators, care providers, and designers to consider interventions that address these challenges.

In constructing interventions for vulnerable populations, the concept of targeted universalism proposes five steps: *Define a universal goal*, *Measure the overall population*, *Measure population segments*, *Understand how structures support or impede*, and *Implement targeted strategies*. While targeted universalism is typically applied in issues of public policy, it has meaningful overlap with health policy and design. When considering the universal goal of improving quality of life for oncology patients, previous research has demonstrated a clear discrepancy between the overall population of patients and the AYA segment for a number of outcomes (Adolescent and Young Adult Oncology Progress Review Group, 2006). The current study adds to the body of literature in *understanding how structures support or impede* – a key step on the way to implementing targeted strategies. The next chapter will further explore the role of the built environment as a physical structure inhibiting the achievement of this universal goal.

Composite Description – The "Essence"

In Moustakas' method, the end result of a phenomenology is synthesis of the textual and structural descriptions – he refers to this process as intuitive integration. The composite description is presented as a very short narrative and seeks to present similarities and themes from the individual narratives – an exercise that sets phenomenological research apart from a collection of related case studies (Munhall,

2007). The composite description, however, does not seek to homogenize the experience and recognizes the (arguably more important) heterogeneity of the cancer journey for young people. As one participant said, “Every kid kind of processes what’s going on in their lives in a different way.”

Adolescents and young adults with cancer are experiencing both physical and psychosocial trials that are uniquely challenging to their age group, ranging from isolation to lack of autonomy and information. These challenges can be helped or hindered by the presence of supportive peers, staff, and environment. As a whole, the essence of cancer as a young person is *unmet needs*.

References

Adolescent and Young Adult Oncology Progress Review Group. (2006). *Closing the gap: Research and care imperatives for adolescents and young adults with cancer* (NIH Publication No. 06-6067). Bethesda, MD: National Cancer Institute, National Institutes of Health, and the LIVESTRONG Young Adult Alliance. Retrieved from https://www.cancer.gov/types/aya/research/ayao-august-2006.pdf

Barkway, P. (2001). Michael Crotty and nursing phenomenology: Criticism or critique? *Nursing Inquiry*, *8*(3), 191–195. https://doi.org/10.1046/j.1320-7881.2001.00104.x

Colaizzi, P. F. (1978). Psychological research as the phenomenologist views it. In R. S. Valle & M. King (Eds.), *Existential Phenomenological Alternatives for Psychology* (pp. 48–71). Oxford: Oxford University Press.

Creswell, J. W. (2007). *Qualitative inquiry and research design: Choosing among five traditions* (2nd ed.). Thousand Oaks, CA: SAGE Publications.

Fochtman, D. (2008). Phenomenology in pediatric cancer nursing research. *Journal of Pediatric Oncology Nursing*, *25*(4), 185–192. https://doi.org/10.1177/1043454208319186

Fochtman, D. (2010). *Understanding the Meaning of the Lived Experience of Adolescents in Treatment for Cancer* (Doctoral dissertation). University of Hawai'i, Mānoa. Retrieved from https://scholarspace.manoa.hawaii.edu/bitstream/10125/22052/2/uhm_phd_fochtman-d_r.pdf

Keegan, T. H. M., Lichtensztajn, D. Y., Kato, I., Kent, E. E., Wu, X.-C., West, M. M., … and the AYA HOPE Study Collaborative Group. (2012). Unmet adolescent and young adult cancer survivors information and service needs: A population-based cancer registry study. *Journal of Cancer Survivorship*, *6*(3), 239–250. https://doi.org/10.1007/s11764-012-0219-9

Kumar, A. R., & Schapira, L. (2013). The impact of intrapersonal, interpersonal, and community factors on the identity formation of young adults with cancer: A qualitative study. *Psycho-Oncology*, *22*(8), 1753–1758. https://doi.org/10.1002/pon.3207

Moerer-Urdahl, T., & Creswell, J. W. (2004). Using transcendental phenomenology to explore the "ripple effect" in a leadership mentoring program. *International Journal of Qualitative Methods*, *3*(2), 19–35.

Moran, D. (2000). Introduction. In *Introduction to Phenomenology*. New York, NY: Routledge.

Moustakas, C. (1994). *Phenomenological Research Methods*. Thousand Oaks, CA: SAGE Publications.

Munhall, P. (2007). A phenomenological method. In *Nursing Research: A Qualitative Perspective* (4th ed.). Sudbury, MA: Jones and Bartlett Publishers.

Potter, J. (2004). Fatigue experience in advanced cancer: A phenomenological approach. *International Journal of Palliative Nursing*, *10*(1), 15–22.

Ream, E., & Richardson, A. (1997). Fatigue in patients with cancer and chronic obstructive airways disease: A phenomenological enquiry. *International*

Journal of Nursing Studies, *34*(1), 44–53. https://doi.org/10.1016/S0020-7489(96)00032-6

Shosha, G. A. (2012). Employment of Colaizzi's strategy in descriptive phenomenology: A reflection of a researcher, *8*(27), 31–43.

Smith, A. W., Parsons, H. M., Kent, E. E., Bellizzi, K., Zebrack, B. J., Keel, G., … Keegan, T. H. M. (2013). Unmet support service needs and health-related quality of life among adolescents and young adults with cancer: The AYA HOPE Study. *Frontiers in Oncology*, *3*. https://doi.org/10.3389/fonc.2013.00075

Stegenga, K., & Ward-Smith, P. (2009). On receiving the diagnosis of cancer: The adolescent perspective. *Journal of Pediatric Oncology Nursing*, *26*(2), 75–80. https://doi.org/10.1177/1043454208328767

Thibodeau, J., & MacRae, J. (1997). Breast cancer survival: A phenomenological inquiry. *Advances in Nursing Science*, *19*(4), 65–74.

Tobin, G. A., & Begley, C. (2008). Receiving bad news: A phenomenological exploration of the lived experience of receiving a cancer diagnosis. *Cancer Nursing*, *31*(5), E31–E39.

Van Manen, M. (1990). *Researching Lived Experience: Human Science for an Action Sensitive Pedagogy*. Albany, NY: SUNY Press.

Van Manen, M. (2016). *Researching Lived Experience: Human Science for an Action Sensitive Pedagogy* (2nd ed.). New York, NY: Routledge.

Woodgate, R. L. (2006). Siblings' experiences with childhood cancer: a different way of being in the family. *Cancer Nursing*, *29*(5), 406–414.

CHAPTER 3 – QUESTIONNAIRE

QUANTIFYING THE IMPACT OF FACILITY DESIGN ON SOCIAL SUPPORT AND QUALITY OF LIFE FOR ADOLESCENTS AND YOUNG ADULTS WITH CANCER THROUGH A NOVEL QUESTIONNAIRE

Cancer is the number one disease-related cause of death in adolescence, surpassed only by accidents, suicide, and homicide. In 2011, nearly six times the number of adolescents were diagnosed with cancer than children, though adolescents are generally treated at the same facilities as younger pediatric patients (National Cancer Institute, 2015). This can be problematic if the facilities are not well-adapted for multiple life stages, as both the physical and psychological needs of adolescent cancer patients differ from those of childhood patients.

Beginning with Roger Ulrich's landmark study of patient recovery and views of nature (1984), researchers have suggested that evidence-based design of the built environment can promote healing. Under Gibson's affordance theory, a well-designed environment encourages and supports certain behaviors without any additional sensory processing from the user (Gibson, 1977). A supportive healthcare environment will provide for social behavior without requiring explicit understanding of the possibilities of the environment. Similarly, Ulrich's theory of supportive design (1991; 2001) posits a healthcare environment can promote wellness, reduce stress, and improve outcomes if patients have the following: a sense of control, access to social support, and access to positive distractions. Understanding the continuum of socialization needs both across the lifespan and between healthcare facilities will provide designers with evidence to create these adaptive facilities that allow for positive, supportive care

through the adolescent development period.

In many instances within the healthcare domain, the boundaries of adolescence do not line up with the boundaries proposed in developmental psychology. Many facilities and agencies discuss AYA (Adolescent and Young Adult) cancer resources, proposing an extended age period usually bound by ages 15 to 39. This recommendation is based in cancer biology, as the types of cancer experienced between ages 15-39 are unique in their origin and treatment (Bleyer, 2007). In developmental psychology domains, the cognitive and social differences between 15-year-old adolescents and 39-year-old adults are extensive. As such, boundaries this large are rarely ever used for the purpose of research on the lifespan. In 2013, the AYA Oncology Progress Research Group recommended continued use of ages 15 to 39 to define this population, while conceding that it may be flexibly applied, specifically mentioning developmentally based definitions as more appropriate in the psychosocial domain (Smith et al., 2016).

Addressing the controversy surrounding the definition of an AYA age range, a number of experts were asked by the Journal of Adolescent and Young Adult Oncology (JAYAO) to provide their recommendation. Several clinicians and researchers recommended divisions between younger and older AYAs, while others provided a specific age range or suggested "college age" ("What should the age range be for AYA oncology?," 2011). For the purpose of this study, the AYA age range will be subdivided as recommended by Sylvie Aubin in the JAYAO editorial – specifically 15-18; 19-24; and 25-39. These divisions are intended to categorize AYAs based on similarity in both physiological and psychosocial developments.

Adequacy of the Built Environment for AYA Populations

Previous studies have investigated adolescent and young adult preferences in the built environment, though most studies rely on younger pediatric participants. In a study of 12- to 14-year-olds in a hospital, participants preferred colors they considered cheerful and bright, but disliked elements they considered to be more childish, including teddy bears and balloons. Private bedrooms, bathrooms, and entertainment opportunities (like television and DVDs) were highly preferred (Blumberg & Devlin, 2006). Similarly, in a qualitative study of 11- to 19-year-olds in a physician's office, participants preferred a less childish environment with home-like characteristics and age-appropriate entertainment (Tivorsak, Britto, Klostermann, Nebrig, & Slap, 2004). In this study, however, participants preferred neutral colors – likely because the participants' age range was older than studied by Blumberg & Devlin (2006). A study of 4- to 16-year old patients in an English hospital resulted in a list of visual cues signifying "babyish" spaces (plastic toys, balloons, play areas, etc.) and spaces for older children and teenagers (computers, posters, televisions, and music) (Birch, Curtis, & James, 2007). A quantitative study of art preferences among hospitalized youth revealed a significant preference for representational nature images, rather than impressionist or abstract images – particularly among ages 14-17 (Eisen, Ulrich, Shepley, Varni, & Sherman, 2008). In an ethnographic study of ward use in an adolescent-designated unit, adolescents often created their own space within the ward, using personal effects to disrupt feelings of homogeneity within the space (Hutton, 2010).

In 2001, clinical nurses in a teenage oncology unit in the UK reflected on the

gap in services provided to AYAs with a brief mention of the ideal treatment environment (Hollis & Morgan, 2001):

> The unit can become a familiar place, with familiar faces in surroundings that should exude hopefulness, normality, and professionalism. It should become a place to which the patient has no fear of returning and where there is mutual trust. It is a place where patients find out that they are not alone, and mutually supportive relationships can form with peers.

Because of the lack of facilities (and literature to support the design of these facilities), this study aims to **measure the discrepancy between AYA patient needs and the current state of the built environment (Aim 1).** In previous interviews with AYAs (Chapter 2), participants described inadequacies in the built environment (Peditto, Shepley, Sachs, Mendle, & Burrow, unpublished). Hypothesis #1 states that participants will report discrepancies between features important to patients and those effectively provided in the treatment environment.

Social Support during Adolescence and Young Adulthood

While adolescents are affected by different types of cancer than children, they also have different psychological needs to fulfill, including a transition in social support needs. In general, social support is the perceived or actual social resources available to a person from non-professionals (Gottlieb & Bergen, 2010). This can incorporate resources from peers, siblings, and parents, and span both formal support groups and informal relationships. This study investigates *perceived* social support from peers – the individual's beliefs about the availability of social resources (Gottlieb & Bergen, 2010). This distinction is important, because perceived support (as opposed

than actual support) has a demonstrated buffering effect on adversity (Barrera, 1986). The social support required for positive outcomes has a demonstrated relationship with the context in which it occurs, including a person's life-stage (Cutrona & Russell, 1987).

Because social support needs (and the avenues through which social support is received) change as children transition to adolescence and to young adulthood, healthcare design must change to facilitate different facets of social support. Both boys and girls experience a shift in perceived support during adolescence, as peer support increases in early adolescence (ages 12-16), decreases in late adolescence (ages 16-18), and becomes comparable to support from parents into adulthood (ages 18+) (Helsen, Vollebergh, & Meeus, 2000). Results from this study, however, echoed the importance of parental support, while suggesting a minimal relationship between peer support and emotional well-being. As the positive influence of parental support is well-documented, the current study hopes to expand on the influence of peer support, particularly for adolescent cancer patients.

In a study of perceived emotional support among 45 adolescents with cancer (ages 12-18), the most frequently reported sources of support were mothers and friends (Ritchie, 2001). A qualitative study of 15 adolescents with cancer (ages 12-18) found similar results, such that adolescents indicated their families, health team, and friends provided their main sources of support (Woodgate, 2006). A systematic and critical review of the literature on social support among adolescents with cancer revealed substantial methodological challenges in this domain, however. With most studies limited by small sample sizes, there is little information on gender and age

differences in social resources. Many studies rely on descriptive qualitative data with very few studies employing a validated quantitative social support measure. Future researchers were urged to consider the relationship between social support and other outcomes (Decker, 2007).

Social Support and Quality of Life

Social support has a demonstrated relationship with health-related quality of life (HRQoL). In a recent study of adult breast cancer survivors, women without partners demonstrated lower levels of social support and poorer HRQoL (Leung, Smith, & McLaughlin, 2016). In a large study of cancer survivors (n = 1768), social support had a significant relationship with physical and mental HRQoL for both genders (Westby, Berg, & Leach, 2016). This relationship has been echoed in domains beyond cancer. A study of HIV-infected men suggested a similar association between increased social support and increased health-related quality of life (Shrestha et al., 2017). In rheumatoid arthritis patients, lower levels of social support were associated with lower HRQoL (Gong & Mao, 2016).

Only recently has research been initiated that investigates the nuances of peer social support and quality of life. One very recent study has demonstrated the influence of peer social support in a young adult population of Korean medical students. As a source of social support, friends were most significantly correlated with *overall* quality of life, while significant others were most influential on psychological and social quality of life (Hwang et al., 2017). Even fewer studies have looked specifically at adolescent or young adult populations. In a recent study of perceived social support and HRQoL, young adult cancer survivors reported greater HRQoL but

lower levels of perceived social support from both peers and family, compared to a control group of non-patients (Tremolada, Bonichini, Basso, & Pillon, 2016). This unusual finding begs more research specifically investigating social support and HRQoL in adolescence, as well as the external influences on these factors, like facility design. The Adolescent and Young Adult Oncology Progress Review Group specifically called on researchers to perform studies investigating HRQoL among the adolescent and young adult population (Smith et al., 2016).

Influence of the Built Environment on Social Support and Quality of Life

The psychosocial standard of care for pediatric oncology stresses the importance of providing opportunities for social interaction – and even briefly implies the built environment may facilitate psychosocial care (Christiansen et al., 2015). To receive the Center for Excellence award designated to AYA cancer facilities, a facility must provide (among other qualifications) psychosocial support for its patients (Health Care Rights Initiative (HCRI), n.d.). The Center for Excellence designation, however, only requires a center establish several formal support services and provide certain resources, making no mention of the facility design that may critically support the efficacy of these resources. In meetings of the AYA Oncology Progress Review Group in 2006 and 2013, researchers and practitioners alike noted the importance of understanding the unique burden of cancer on adolescents, as well as the importance of providing developmentally-oriented care (Adolescent and Young Adult Oncology Progress Review Group, 2006; Smith et al., 2016). Like the Center for Excellence standards, however, there is no mention of the built environment.

The relationship between the built environment and social support has been

previously established, although in community and not medical settings. The presence of porches, for example, positively influenced perceived social support in a Hispanic neighborhood, with perceived social support mediating the relationship between the built environment and psychological distress (Brown et al., 2009). In a Swedish neighborhood, residents reported a significant increase in social support during a 10-year longitudinal study after community development projects improved the schools, playgrounds, shops, and youth activities (Dalgard & Tambs, 1997). Older adults living in deteriorated neighborhoods report lower social support than those living in well-maintained neighborhoods (Thompson & Krause, 1998).

At the facility scale, this study aims to measure the mediating effect of perceived social support on the relationship between the built environment and health-related quality of life for AYAs (Aim 2). Because of the established relationship between social support and quality of life, Hypothesis #2 states that the relationship between adequate facilities and health-related quality of life is mediated by perceived social support, such that adequacy of the built environment will influence perceived social support, while perceived social support influences quality of life (see Figure 3.1).

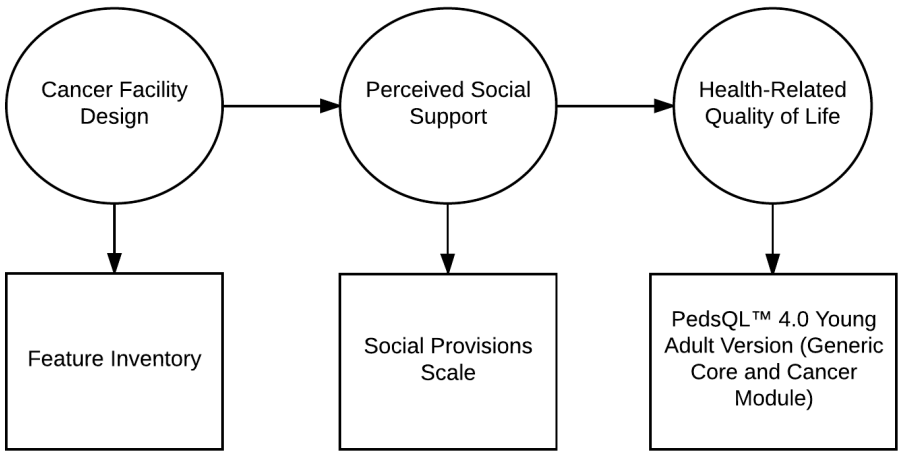


Figure 3.1. The conceptual framework of the study demonstrating the constructs and measures being investigated and their hypothesized relationship (Aim 2).

Methods

Questionnaire Development

Health-related quality of life was measured using an adaptation of the previously validated Pediatric Quality of Life Inventory™ (PedsQL) Generic Core Scale for Young Adults (Varni & Limbers, 2009) and the corresponding Cancer Module for Young Adults (Varni, Burwinkle, Katz, Meeske, & Dickinson, 2002). The original PedsQL for Young Adults was intended for and tested with participants aged 18 to 25. The core scale includes items in four categories: Physical Functioning, Emotional Functioning, Social Functioning, and Study/Work Functioning. The cancer module includes an additional eight categories: Pain & Hurt, Nausea, Procedural Anxiety, Treatment Anxiety, Worry, Cognitive Problems, Perceived Physical Appearance, and Communication. To best fit the age range of the proposed sample, this questionnaire used the adaptation of the PedsQL created by Ewing, King, and

Smith (2009) in their validation study involving cancer and blood disorder patients aged 16 to 32. Ewing et al. validated this adaptation of the PedsQL with a Cronbach's alpha ranging from 0.81 to 0.98. This adaptation was also approved by the original developer, James Varni, as indicated by Ewing, King, and Smith (2009). It has been recommended for use by the Adolescent and Young Adult Oncology Progress Review Group for studies investigating HRQoL (Smith et al., 2016).

While the PedsQL contains five items on social functioning, these do not represent the level of perceived peer support from other patients in the facility. To investigate perceived peer support, the Social Provisions Scale (SPS) (Russell & Cutrona, 1984) was also administered. The discriminant validity of the SPS has been previously investigated and it has been determined to be distinct from measures of social desirability, introversion-extraversion, and neuroticism. It has also been previously used in studies of the elderly, showing a significant relationship between SPS scores and several health outcomes, particularly when participants were under high stress (Cutrona & Russell, 1987). The Social Provisions Scale was adapted slightly, as it currently reads "…Think about your current relationships with friends, family members, co-workers, community members, and so on." To better address the construct of peer social support, the instructions were amended to "Think about your current relationships with peers in this facility," "Think about your relationships with peers in your facility while you were being treated," and similar sentiments.

Participants were also asked about the importance and effectiveness of features from a design inventory, following the structure used by Shepley et al. 2017. Consideration was given to adapting the Physical and Architectural Characteristics

Inventory (PACI) (Timko, 1996) as a tool, but in its original form the PACI contains only one section regarding "social-recreational aids," and only suggests two features within these categories – the presence of small tables and the presence of a patio or courtyard. As such, a novel inventory was best suited.

The inventory was constructed using information gathered during the previous interviews, site visits to identified facilities, and a survey of healthcare design professionals.

Expert survey. To ensure a comprehensive feature inventory, 11 experts were provided a list of inpatient features for AYA patients that they rated on a 5-point Likert scale for importance and asked to provide recommendations for missing features. Paper surveys were distributed to attendees at the Healthcare Planning, Design, and Construction (PDC) Summit in Nashville, TN in March 2018 using a snowball sampling technique, in which one participant (identified prior to the PDC Summit) assisted in identifying other experts attending the summit.

Experts who did not attend the PDC Summit were asked to complete an online version of the same questionnaire through Qualtrics (see Appendix A) – these participants were also identified through snowball sampling. Participants were both male and female, ages 29 – 70, experts in the fields of healthcare planning and design (several with experience in projects related to AYA cancer), with titles ranging from interior designer to architect to principal and architectural intern to senior vice president.

The feature inventory was adjusted based on open-ended feedback on the expert questionnaire. The wording "quiet room" was changing to "meditative space,"

"open/enclosed nursing station" was removed due to confusion, and "artwork" was added. One expert noted the importance of thermal comfort, so "temperature control" was added. Experts also suggested several other features, including infection control and a space for clinicians, but these were not included as they were not directly patient-related.

Pilot study. The questionnaire was piloted with six participants ages 18 – 28 to evaluate the tool prior to deployment. Members of the Young Adult Support Group of the Cancer Resource Center of the Finger Lakes in Ithaca, NY participated in the pilot study. Pilot feedback resulted in the addition of a new section addressing patient-patient social interaction, using the following questions: "Were you satisfied with your ability to interact with other patients your age?" (Yes/No, I would have preferred more/No, I would have preferred less); and "How did you meet other patients your age?" (In the hallways of my treatment facility/In the common areas of my treatment facility/During outpatient treatment/I was introduced by someone else/In a support group/Through involvement with an organization/Online/Other). The final tool is included in Appendix B.

Participants

Participants were ages 15 to 39, both male and female, and have received (or currently receiving) treatment for a cancer diagnosis. Exclusion criteria for participants included co-morbid diagnoses, any major developmental disorders, receiving end-of-life care, and/or diagnosed less than three months' prior (adapted from Ewing et al., 2009).

Participants were recruited through outreach by various AYA cancer

organizations, including the Ulman Fund, Teen Cancer America, The Samfund, First Descents, and True North Treks. These organizations shared the study information on various social media channels, private Facebook groups, and listservs.

At the time of the survey, 85% of participants were categorized as late young adults between the ages of 25-39, though 33% of participants were first diagnosed prior to age 25 during adolescence and early young adulthood. Participants were treated at 42 different inpatient facilities and 55 outpatient facilities across the US, ranging from large academic health systems to private specialty clinics. Most patients had experience with both inpatient and outpatient facilities, and 38% of participants also had emergency room experience. Twenty-five percent of participants had access to a specialized AYA program or AYA resources. Of the participants that provided a diagnosis, Hodgkin's and non-Hodgkin's lymphoma were most commonly reported, comprising 29% of the sample (see Table 3.1).

Table 3.1

Frequency Statistics by Demographic Variables

Characteristic	*n*	%
Age at time of survey		
< 15	0	0
15-18	1	1.0
19-24	6	5.7
25-39	88	84.6
> 39	9	8.7
Age at first diagnosis		
< 15	4	3.8
15-18	10	9.6
19-24	20	19.2
25-39	70	67.3
> 39	0	0
Age when treatments completed		
< 15	0	0
15-18	10	9.6
19-24	14	13.5
25-39	63	60.6
> 39	1	1.0
Currently receiving treatment	16	15.4
Time since last treatment		
Within six months	9	8.7
Within last year	12	11.5
Within last two years	16	15.4
Over two years ago	48	46.2
Currently receiving treatment	16	15.4
Type of cancer (SEER categories)		
Carcinoma	11	10.6
Sarcoma	8	7.7
Myeloma	1	1.0
Leukemia	13	12.5
Lymphoma	30	28.8
Mixed Types	0	0
Unspecified	41	39.4

Type of facilities		
Inpatient only	8	7.7
Outpatient only	24	23.1
Inpatient and outpatient	33	31.7
Inpatient and emergency	3	2.9
Outpatient and emergency	3	2.9
Inpatient, outpatient, emergency	33	31.7
Access to AYA program or resources		
Yes	26	25.0
No	54	51.9
Unsure	24	23.1

Distributing the questionnaire publicly on social media led to an unforeseen challenge – an influx of ineligible (or spam) respondents, likely incentivized by the $10 Amazon gift card reward. These spam respondents were not deterred by the implementation of a CAPTCHA nor by a question that required participants to email the PI to receive a password. To systematically remove ineligible participants without compromising the sample, the following criteria were implemented: 1) If a participant indicated that they were still receiving treatment, they must not have reported an age at which treatments were completed, 2) If a participant reported a number instead of listing a site name when asked to indicate where they were treated, they were excluded, and/or 3) If a participant selected that their treatments were completed "over two years ago," but their reported current age and the age at which their treatments were completed were within a year, they were excluded.

Results

Adequacy of the Built Environment

Participants were first asked to rate the importance of environmental qualities in an AYA treatment environment. "Autonomy over decisions" and "interaction with

significant others" were considered the most important qualities by participants, while "opportunity to continue classes," "interaction with other patients," and "career exploration" were considered least important (see Table 3.2). Participants also provided rankings for environmental characteristics that may contribute to the achievement of goals during adolescence and young adulthood. The majority of participants ranked private bedrooms as the most important feature for a number of goals, including identity development (79.8%), independence (75.0%), relationships with friends and family (47.1%), and intimate relationships (83.7%). Access to internet resources and indoor therapy areas were ranked the most important environmental characteristics for future achievement by 49.0% and 40.4% of participants, respectively.

Table 3.2

Mean Ratings of Importance for Environmental Qualities in an AYA Setting

Qualities	*M* (*SD*)
Autonomy over decisions	4.47 (0.72)
Interaction with significant others	4.40 (0.76)
Independence	4.28 (0.88)
Privacy	4.24 (0.95)
Interaction with outside friends	4.21 (0.82)
Autonomy over appearance	4.06 (0.96)
Opportunity to explore interests and hobbies	3.81 (1.03)
Physical contact with others	3.71 (1.14)
Interaction with parents	3.81 (1.08)
Opportunity to continue classes	3.69 (1.18)
Interaction with other patients	3.69 (1.18)
Career exploration	3.66 (1.20)

All participants (n = 104) were then asked to rate the importance of environmental characteristics, but only those who were currently being treated or had completed treatment within the last two years (n = 56) were asked to rate the effectiveness of those characteristics. All participants' responses are included for mean ratings of importance, while mean ratings of effectiveness are only reported for the cohort of participants with the most recent experience in a treatment setting (n = 56). Paired t-tests were performed using only the data from the participants with the most recent experience (see Table 3.3). Although Wilcoxon's signed-rank test (a non-parametric approach) is often recommended for Likert-style ordinal data, t-tests have been shown to reduce Type II error in simulations of Likert data, even with small sample sizes when assumptions have been violated (Meek, Ozgur, & Dunning, 2007).

Because many participants rated outdoor space so high in importance, there were several negative outliers in the ratings for outdoor space that remained in the data for analysis. The difference scores for the importance and effectiveness were approximately normally distributed as assessed by examination of a Normal Q-Q plot for each characteristic. A negative t-value indicates that the participant rated the characteristic as less effective than it was rated important (implying an inadequacy in the built environment). Ratings were provided on a 5-item Likert scale. Participants indicated a significant discrepancy between mean importance and effectiveness for all 22 environmental characteristics ($p \leq .004$), supporting Hypothesis #1 (see Table 3.3).

Table 3.3

Summary of Paired t*-tests for Adequacy of the Built Environment*

	M (*SD*)			
Facility/Unit Features	Importance	Effectiveness	*t*	*p*
Outdoor space	4.42 (0.75)	2.07 (1.26)	-12.87	< .001
Patient-only lounge	2.98 (1.06)	1.45 (0.83)	-10.58	< .001
Meditative space	3.62 (1.01)	1.66 (1.15)	-9.76	< .001
Daylight	4.68 (0.64)	3.18 (1.13)	-9.19	< .001
Classroom	2.74 (0.95)	1.45 (0.93)	-9.01	< .001
Access to kitchen	3.39 (0.99)	1.88 (1.11)	-8.81	< .001
Motivational message board	3.18 (0.94)	2.11 (1.28)	-8.01	< .001
Internet and computer resources	4.67 (0.63)	3.43 (1.26)	-7.82	< .001
Family-patient lounge	3.76 (0.97)	2.30 (1.31)	-7.76	< .001
Artwork	3.53 (1.08)	2.43 (1.19)	-4.95	< .001
Moveable seating	3.63 (1.01)	2.95 (1.20)	-4.90	< .001
Small number of patients per unit	3.88 (0.95)	2.95 (1.38)	-4.77	< .001
Recreation (TV, games)	3.91 (1.04)	3.07 (1.44)	-3.00	.004
Patient Room Features				
Visitor beds in patient rooms	4.26 (0.84)	2.29 (1.37)	-10.31	< .001
Temperature control	4.61 (0.69)	2.32 (1.43)	-10.20	< .001
Personalizable rooms	3.32 (1.02)	1.80 (1.20)	-9.23	< .001
Personal desk space	3.60 (1.13)	1.70 (1.01)	-7.39	< .001
Private bathrooms	4.76 (0.65)	3.13 (1.82)	-7.02	< .001
Private bedrooms	4.70 (0.65)	3.45 (1.64)	-6.39	< .001
Personal closet space	3.53 (1.14)	2.59 (1.55)	-5.46	< .001
Clinical Features				
Therapy area (PT, OT, art, music)	4.23 (0.84)	2.48 (1.56)	-8.20	< .001
Staff-patient consulting area	3.79 (0.97)	2.88 (1.42)	-5.39	< .001

Influence of the Built Environment on Social Support and Quality of Life

There was a significant positive correlation between perceived social support and HRQoL, $r_s = .383$, $p < .001$. Participants' difference scores between importance and effectiveness for all 22 characteristics were averaged to create a single "adequacy" score for each individual. Addressing Hypothesis #2, there was not a significant correlation between the adequacy of the environment and HRQoL, $r_s = .091$. Though adequacy of the built environment as a whole was not significantly associated with social support or HRQoL, the efficacy of several specific environmental features demonstrated a significant positive correlation with perceived social support, with coefficients ranging from $r = .26$ (private bedrooms) to $r = .30$ (recreation).

Table 3.4

Summary of Significant Correlations between Features and Perceived Social Support

Feature	*r*	*p*
Recreation (TV, games)	.304	.023
Internet and computer resources	.286	.033
Moveable seating	.265	.048
Private bedrooms	.258	.055
Private bathrooms	.259	.054

A multiple regression was performed to predict health-related quality of life from adequacy of the built environment, access to AYA resources, satisfaction with patient-patient interaction, and perceived social support. HRQoL scores were approximately normally distributed. There was independence of residuals, as assessed by a Durbin-Watson statistic of 1.94. Linearity and homoscedasticity were

demonstrated by visual inspection of a plot of studentized residuals versus unstandardized predicted values for each factor. There was no evidence of multicollinearity as assessed by tolerance levels greater than 0.10. Although there were several leverage points, there were no outliers in the data and calculation of Cook's Distance indicated no points with a high degree of influence (Cook's Distance < 1.00).

Adequacy of the built environment, access to an AYA program, satisfaction with patient-patient interaction, and perceived social support significantly predicted HRQoL, $F(4, 51) = 3.26$, $p = .019$. R^2 for the overall model was 20.4% with an adjusted R^2 of 14.1%, $f^2 = .164$ – a medium effect size, according to Cohen (1992). Further, in clinical outcomes studies with high ecological validity (as opposed to those conducted in controlled environments), a model with an R^2 value of 0.204 can indicate clinical relevance (Hamilton, Ghert, & Simpson, 2015). A summary of the regression model is found in Table 3.4.

Table 3.5

Summary of Multiple Regression Analysis

Variable	*B*	SE_B	β	*t*	*p*
Intercept	63.36	17.85			
Perceived Social Support	0.28	0.15	.24	1.87	.068
Adequacy of the Built Environment	2.95	2.61	.16	1.13	.264
Satisfaction with Patient-Patient Interaction	14.17	5.74	.35	2.47	.017
Access to an AYA Program	0.522	4.098	.371	.371	.712

Discussion

Adequacy of the Built Environment

All 22 environmental characteristics were found to be significantly inadequate, with "outdoor space," "patient-only lounge," "visitor beds in patient rooms," "meditative space," "temperature control," and "personalizable rooms" considered the most inadequate (see Table 3.3).

The importance of outdoor space has long been touted in the health design community, though many facilities still provide inadequate opportunities. When considering how outdoor space may be implemented, it may be more nuanced than simply a healing garden – in some studies, participants have indicated value for *any* space that allows patients to spend time outside of the hospital room or ward (Whitehouse et al., 2001; Birch et al., 2007). In an oncology setting, this flexible definition of "outdoor space" may be necessary, as immune-compromised patients may not be afforded the opportunity to access a ground-floor garden. Consideration must also be given to the image concerns of AYAs – results from Chapter 1 indicated body image issues as a barrier to using public hospital spaces (Peditto, Shepley, Sachs, Mendle, & Burrow, unpublished).

For this reason, "patient-only lounges" and "visitor beds in patient rooms" become important as opportunities for social connection, bridging the gap between public and private spaces. In a previous study, the dining room functioned in this way for patients seeking interaction – patients considered the dining room "a welcome opportunity to interact without obligation" (Larsen, Larsen, & Birkelund, 2014). More consideration for the role of the built environment and social behavior is given in the

following section. Similarly, the role of "temperature control" and "personalizable rooms" are discussed further in the following section, as they relate to salient issues of control and choice.

Given the lack of literature on the health design preferences of AYAs and the small number of AYA-dedicated facilities in the United States, these findings are unsurprising but indicate a need for age-specific design guidelines. Future research (included in the following chapter) employs participatory design focus groups to explore the most inadequate characteristics with specific recommendations for their implementation.

Influence of the Built Environment on Social Support and Quality of Life

Results of the regression model demonstrate the importance of social connections with other patient-peers as it relates to health-related quality of life. Results from earlier interviews with 16 adolescents and young adults with cancer indicate a number of barriers to peer interaction in health facilities, including HIPAA restrictions and lack of information from clinicians and care providers. Many AYAs are left to seek peer-patient connections on their own (Peditto, Shepley, Sachs, Mendle, & Burrow, unpublished). In the current study, nearly half of all participants met same-age patients through support groups, involvement with an AYA organization, or online. 37% of participants, however, indicated they met peer-patients during outpatient treatment, or in the hallways and common areas of their treatment facility, further emphasizing the role of the built environment in facilitating peer-patient interaction.

Optimization between privacy and interaction. Although "interaction with

other patients" was rated as one of the least important environmental qualities, 86% of participants indicated that they would have preferred more interaction with other patients their age. Only 11% of participants indicated that they had as much as interaction with other patients as they desired. These contradictory findings may result from a desire not simply for social opportunities, but for a *balance* between privacy and social interaction.

In the current study, the correlations between certain environmental characteristics and social support emphasize the important balance of privacy and interaction. While recreation areas, Internet access, and moveable seating all contribute explicitly to social opportunity, the correlation between social support and private bedrooms and bathrooms hints at the optimization process between privacy and desired social interaction.

In an oncology setting, providing a balance between privacy and social interaction is arguably even more important than simply affording social interaction. In a study of 243 young adults, 82% of participants reported seeking privacy when they were distressed. 81% of those participants reported "feeling better" after seeking privacy (Newell, 1994). In a previous qualitative study (Study 1) (Peditto, Shepley, Sachs, Mendle, & Burrow, unpublished), when asked to describe their ideal treatment facility, a number of AYAs described this balance. As one example, an AYA participant mentioned:

> *You might have visitors, you might not. If you have visitors, you might want more privacy but if you wanted to socialize with other people, it's super awkward, it's like you're violating HIPAA. So, it may be some sort of*

compromise between the two things.

When asked to describe their privacy needs, a group of adolescents previously hospitalized for cancer treatment emphasized the importance of the environment, indicating their appreciation for curtains, in-room telephones, and en-suite private bathrooms (Hutton, 2002). An ethnographic study of 40- to 79-year-olds being treated for cancer suggested that patients often seek refuge from fellow patients – and that their ability to seek refuge depends on the ward architecture, as patients were observed using different rooms in the hospital to regulate privacy (Larsen et al., 2014).

Issues of choice and control. As personal privacy is related to control (Malcolm, 2005), these findings may extend to broader issues of choice and control, such that patients desire control over their environment – social and otherwise. Participants indicated significant inadequacies in "temperature control," "personalizable rooms," and "access to kitchen" – characteristics that contribute to a sense of autonomy. Likewise, "Autonomy over decisions" was ranked the most important environment quality by participants in the current study. Previous research shows an association between cancer and a loss of personal autonomy in decision-making (Denieffe & Gooney, 2011). In a study of patients ages 4-16 at an English hospital, participants were less concerned with aesthetic characteristics and more concerned with their ability to control lighting, temperature, noise, and smell (Birch et al., 2007).

Limitations

There were several limitations of note in this study. It is unknown how AYAs not recruited for the study may have answered this questionnaire. Recruiting

participants required outreach from AYA support organizations – AYAs who have not connected to these resources (electively or otherwise) did not have the opportunity to complete this survey. There may be important distinctions and needs for AYAs who do not (or choose not to) engage with outside organizations.

Additionally, it is unknown how participants' answers may have changed with less time between treatment and completion of the questionnaire. A number of participants were reflecting on their cancer experience after several years. Future research may consider administering the questionnaire during active treatment.

Conclusion

The current study demonstrated the inadequacy of the built environment for adolescents and young adults with cancer, while emphasizing the importance of AYA-specific resources and opportunities for social support. When designing an inpatient or outpatient cancer facility for young people, designers must consider creating space for social interchange such that patients can engage with others when desired while still ensuring privacy.

Future research in facility design for adolescents and young adults should take a more nuanced approach by considering the full spectrum of social regulatory activities from privacy to casual interactions to planned interactions – and with whom those activities occur. A behavior-mapping study, for example, could reveal the ways in which the built environment affords social regulation among AYAs. While the current study specifically considered cancer facilities, these findings may be generalized to other inpatient and outpatient facilities treating young people – particularly those that provide care for patient populations across the adolescent and

young adult lifespan, like university health facilities and juvenile behavioral health centers.

References

Adolescent and Young Adult Oncology Progress Review Group. (2006). *Closing the gap: Research and care imperatives for adolescents and young adults with cancer* (NIH Publication No. 06-6067). Bethesda, MD: National Cancer Institute, National Institutes of Health, and the LIVESTRONG Young Adult Alliance. Retrieved from https://www.cancer.gov/types/aya/research/ayao-august-2006.pdf

Barrera, M. (1986). Distinctions between social support concepts, measures, and models. *American Journal of Community Psychology*, *14*(4), 413–445. https://doi.org/10.1007/BF00922627

Birch, J., Curtis, P., & James, A. (2007). Sense and sensibilities: In search of the child-friendly hospital. *Built Environment*, *33*(4), 12.

Bleyer, A. (2007). Young adult oncology: The patients and their survival challenges. *CA: A Cancer Journal for Clinicians*, *57*(4), 242–255.

Blumberg, R., & Devlin, A. S. (2006). Design issues in hospitals: The adolescent client. *Environment and Behavior*, *38*(3), 293–317.

Brown, S. C., Mason, C. A., Lombard, J. L., Martinez, F., Plater-Zyberk, E., Spokane, A. R., … Szapocznik, J. (2009). The relationship of built environment to perceived social support and psychological distress in Hispanic elders: The role of "eyes on the street." *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *64B*(2), 234–246. https://doi.org/10.1093/geronb/gbn011

Christiansen, H. L., Bingen, K., Hoag, J. A., Karst, J. S., Velázquez-Martin, B., & Barakat, L. P. (2015). Providing children and adolescents opportunities for social interaction as a standard of care in pediatric oncology. *Pediatric Blood & Cancer*, *62*(S5), S724–S749. https://doi.org/10.1002/pbc.25774

Cohen, J. (1992). A power primer. *Psychological Bulletin*, *112*(1), 155–159.

Cutrona, C. E., & Russell, D. W. (1987). The provisions of social relationships and adaptation to stress. In D. Perlman & W. H. Jones (Eds.), *Advances in Personal Relationships: A Research Annual*. Greenwich, Connecticut: JAI.

Dalgard, O. S., & Tambs, K. (1997). Urban environment and mental health: A longitudinal study. *The British Journal of Psychiatry*, *171*(6), 530–536. https://doi.org/10.1192/bjp.171.6.530

Decker, C. L. (2007). Social support and adolescent cancer survivors: A review of the literature. *Psycho-Oncology*, *16*(1), 1–11. https://doi.org/10.1002/pon.1073

Denieffe, S., & Gooney, M. (2011). A meta-synthesis of women's symptoms experience and breast cancer. *European Journal of Cancer Care*, *20*(4), 424–435. https://doi.org/10.1111/j.1365-2354.2010.01223.x

Eisen, S. L., Ulrich, R. S., Shepley, M. M., Varni, J. W., & Sherman, S. (2008). The stress-reducing effects of art in pediatric health care: art preferences of healthy children and hospitalized children. *Journal of Child Health Care*, *12*(3), 173–190. https://doi.org/10.1177/1367493508092507

Ewing, J. E., King, M. T., & Smith, N. F. (2009). Validation of modified forms of the PedsQL generic core scales and cancer module scales for adolescents and

young adults (AYA) with cancer or a blood disorder. *Quality of Life Research*, *18*(2), 231–244. https://doi.org/10.1007/s11136-008-9424-4

Gibson, J. J. (1977). The theory of affordances. In R. E. Shaw & J. Bransford (Eds.), *Perceiving, Acting, and Knowing*. Hillsdale, NJ: Lawrence Erlbaum Associates.

Gong, G., & Mao, J. (2016). Health-related quality of life among chinese patients with rheumatoid arthritis: The predictive roles of fatigue, functional disability, self-efficacy, and social support. *Nursing Research*, *65*(1), 55–67. https://doi.org/10.1097/NNR.0000000000000137

Gottlieb, B. H., & Bergen, A. E. (2010). Social support concepts and measures. *Journal of Psychosomatic Research*, *69*(5), 511–520. https://doi.org/10.1016/j.jpsychores.2009.10.001

Hamilton, D. F., Ghert, M., & Simpson, A. H. R. W. (2015). Interpreting regression models in clinical outcome studies. *Bone & Joint Research*, *4*(9), 152–153. https://doi.org/10.1302/2046-3758.49.2000571

Health Care Rights Initiative (HCRI). (n.d.). Change it Back: Centers of Excellence Program. Retrieved March 22, 2017, from http://hcri.org/programs/change-it-back/

Helsen, M., Vollebergh, W., & Meeus, W. (2000). Social support from parents and friends and emotional problems in adolescence. *Journal of Youth and Adolescence*, *29*(3), 319–335. https://doi.org/10.1023/A:1005147708827

Hollis, R., & Morgan, S. (2001). The adolescent with cancer—at the edge of no-man's land. *The Lancet Oncology*, *2*(1), 43–48.

Hutton, A. (2002). The private adolescent: Privacy needs of adolescents in hospitals. *Journal of Pediatric Nursing*, *17*(1), 67–72.

Hutton, A. (2010). How adolescent patients use ward space. *Journal of Advanced Nursing*, *66*(8), 1802–1809.

Hwang, I. C., Park, K. H., Kim, J. J., Yim, J., Ko, K. P., Bae, S. M., & Kyung, S. Y. (2017). Perceived social support as a determinant of quality of life among medical students: 6-month follow-up study. *Academic Psychiatry*, *41*(2), 180–184. https://doi.org/10.1007/s40596-016-0503-5

Larsen, L. S., Larsen, B. H., & Birkelund, R. (2014). A companionship between strangers - the hospital environment as a challenge in patient-patient interaction in oncology wards. *Journal of Advanced Nursing*, *70*(2), 395–404. https://doi.org/10.1111/jan.12204

Leung, J., Smith, M. D., & McLaughlin, D. (2016). Inequalities in long term health-related quality of life between partnered and not partnered breast cancer survivors through the mediation effect of social support. *Psycho-Oncology*, *25*(10), 1222–1228. https://doi.org/10.1002/pon.4131

Malcolm, H. A. (2005). Does Privacy Matter? Former patients discuss their perceptions of privacy in shared hospital rooms. *Nursing Ethics*, *12*(2), 156–166. https://doi.org/10.1191/0969733005ne772oa

Meek, G., Ozgur, C., & Dunning, K. (2007). Comparison of the t vs. Wilcoxon Signed-Rank Test for Likert Scale data and small samples. *Journal of Modern Applied Statistical Methods*, *6*(1). https://doi.org/10.22237/jmasm/1177992540

National Cancer Institute. (2015). Adolescents and young adults with cancer. Retrieved October 11, 2017, from https://www.cancer.gov/types/aya

Newell, P. B. (1994). A systems model of privacy. *Journal of Environmental Psychology*, *14*(1), 65–78. https://doi.org/10.1016/S0272-4944(05)80199-9

Peditto, K., Shepley, M. M., Sachs, N., Mendle, J., & Burrow, A. (unpublished). Cancer during adolescence and young adulthood: A phenomenological exploration of unmet needs.

Ritchie, M. A. (2001). Sources of emotional support for adolescents with cancer. *Journal of Pediatric Oncology Nursing*, *18*(3), 105–110.

Russell, D. W., & Cutrona, C. E. (1984). *Social provisions scale*. Iowa State University.

Shrestha, R., Copenhaver, M., Bazazi, A. R., Huedo-Medina, T. B., Krishnan, A., & Altice, F. L. (2017). A moderated mediation model of HIV-related stigma, depression, and social support on health-related quality of life among incarcerated Malaysian men with HIV and opioid dependence. *AIDS and Behavior*, *21*(4), 1059–1069. https://doi.org/10.1007/s10461-017-1693-x

Smith, A. W., Seibel, N. L., Lewis, D. R., Albritton, K. H., Blair, D. F., Blanke, C. D., … Zebrack, B. J. (2016). Next steps for adolescent and young adult oncology workshop: An update on progress and recommendations for the future. *Cancer*, *122*(7), 988–999. https://doi.org/10.1002/cncr.29870

Thompson, E. E., & Krause, N. (1998). Living Alone and Neighborhood Characteristics as Predictors of Social Support in Late Life. *The Journals of*

Gerontology: Series B, *53B*(6), S354–S364. https://doi.org/10.1093/geronb/53B.6.S354

Timko, C. (1996). Physical characteristics of residential psychiatric and substance abuse programs: Organizational determinants and patient outcomes. *American Journal of Community Psychology*, *24*(1), 173–192.

Tivorsak, T. L., Britto, M. T., Klostermann, B. K., Nebrig, D. M., & Slap, G. B. (2004). Are pediatric practice settings adolescent friendly? An exploration of attitudes and preferences. *Clinical Pediatrics*, *43*(1), 55–61.

Tremolada, M., Bonichini, S., Basso, G., & Pillon, M. (2016). Perceived social support and health-related quality of life in AYA cancer survivors and controls. *Psycho-Oncology*, *25*(12), 1408–1417. https://doi.org/10.1002/pon.4072

Ulrich, R. S. (1984). View through a window may influence recovery from surgery. *Science*, *224*(4647), 420–421.

Ulrich, R. S. (1991). Effects of interior design on wellness: Theory and recent scientific research. *Journal of Health Care Interior Design*, *3*(1), 97–109.

Ulrich, R. S. (2001). Effects of healthcare environmental design on medical outcomes. In *Design and Health: Proceedings of the Second International Conference on Health and Design. Stockholm, Sweden: Svensk Byggtjanst* (pp. 49–59).

Varni, J. W., Burwinkle, T. M., Katz, E. R., Meeske, K., & Dickinson, P. (2002). The PedsQL™ in pediatric cancer. *Cancer*, *94*(7), 2090–2106.

Varni, J. W., & Limbers, C. A. (2009). The PedsQL™ 4.0 Generic Core Scales Young Adult Version: Feasibility, reliability and validity in a university student

population. *Journal of Health Psychology*, *14*(4), 611–622. https://doi.org/10.1177/1359105309103580

Westby, R. P., Berg, C. J., & Leach, C. (2016). Gender, race, BMI, and social support in relation to the health-related quality of life of cancer survivors: A report from the American Cancer Society's Study of Cancer Survivors II (SCS-II). *Quality of Life Research*, *25*(2), 409–421. https://doi.org/10.1007/s11136-015-1084-6

What should the age range be for AYA oncology? (2011). *Journal of Adolescent and Young Adult Oncology*, *1*(1), 3–10. https://doi.org/10.1089/jayao.2011.1505

Whitehouse, S., Varni, J. W., Seid, M., Cooper-Marcus, C., Ensberg, M. J., Jacobs, J. R., & Mehlenbeck, R. S. (2001). Evaluating a children's hospital garden environment: Utilization and consumer satisfaction. *Journal of Environmental Psychology*, *21*(3), 301–314. https://doi.org/10.1006/jevp.2001.0224

Woodgate, R. L. (2006). The importance of being there: Perspectives of social support by adolescents with cancer. *Journal of Pediatric Oncology Nursing*, *23*(3), 122–134. https://doi.org/10.1177/1043454206287396

CHAPTER 4 – FOCUS GROUPS

EVALUATING PREFERENCES OF ADOLESCENTS AND YOUNG ADULTS IN THE CANCER TREATMENT ENVIRONMENT

To expand on the results of Chapter 3 and provide design guidelines for practitioners, the current study seeks to identify specific design elements contributing to a supportive treatment environment for AYAs with cancer. In Chapter 3, the researcher identified four environmental qualities rated most important by AYA participants on a previous survey: *autonomy over decisions*, *privacy*, *control over social interaction*, and *independence*. Control over social interaction is used here to represent interaction with significant others, outside friends, family, and other patients. These dimensions can all be considered under the larger umbrella of issues of control (see Figure 4.1). In existing literature, these dimensions are supported by a number of specific environmental characteristics.

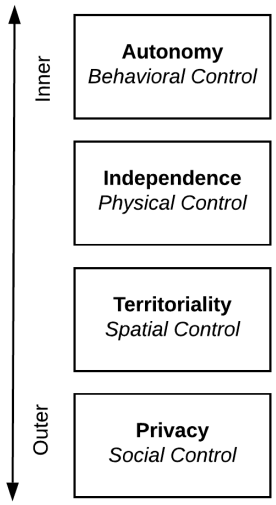


Figure 4.1. A diagram relating different dimensions of control.

Issues of Control

Autonomy. Placed at the top of the hierarchical model in the current study, autonomy is considered broadly as "freedom of choice" (Proshansky, Ittleson, & Rivlin, 1970). Establishing this freedom is considered one of the fundamental goals of adolescent and young adulthood (Hill, 1983), with independence, territoriality, and privacy all contributing to the achievement of autonomy. In an exploration of family-caregiver relationships, researchers defined autonomy as:

> The exercise of self-determined, goal-oriented behavior that is or can be potentially threatened or inhibited by a variety of circumstances, real or symbolic, intrinsic or external to the person (Horowitz, Silverstone, & Reinhardt, 1991).

In a health setting, the barriers to autonomy are often more numerous than the affordances. As an example of inhibiting circumstances, the built environment often disables freedom of choice for patients. As a whole, shared settings (like hospitals) reduce the number of private spaces, with bathrooms, kitchens, and lounges becoming partially owned (Lawton, 1985). This spatial loss can result in a loss of autonomy and control. Lawton (1985) describes the balance of autonomy and support in aging, such that a "turn toward support necessarily limits the person's autonomy or sense of control over their turf."

Under Lawton's theory, individuals with greater knowledge of their surroundings and understanding of the nuances of their environment require less support and gain greater autonomy. By minimizing the amount of patient relocation, hospitals can allow patients to develop environmental competency. This competency

may be in the form of a favorite chair or the arrangement of personal objects in a room – indicating some overlap with territoriality.

Independence. Autonomy and independence, while often used interchangeably, have distinguishing features in the context of health environments. Namely, independence is a contributing dimension of personal autonomy (Davies, Laker, & Ellis, 1997). In comparison to autonomy, independence places more importance on a patient's physical functioning – "the ability to perform the activities of daily living unaided" (Davies et al., 1997).

Like autonomy, however, the barriers in the health environment to patient independence are numerous. The Environment-Independence Interaction Scale identifies several of these barriers under four domains: temporal, social, physical, and cultural (Teel, Dunn, Jackson, & Duncan, 1997). In the physical environment, wayfinding and signage issues can limit independent function in a hospital setting. Similarly, the distance of patient rooms to other important areas can make it difficult for patients to navigate independently. Proper lighting can ensure that patients participate safely in independent activities.

Territoriality and privacy. Privacy is distinguished from territoriality, though the two may overlap or occur simultaneously, as happens in one's home where an individual has both territory and privacy (Edney & Buda, 1976). Some researchers consider privacy a form of territoriality (Pastalan, 1970), while others consider territoriality a means of achieving of privacy (Altman, 1975). Through the achievement of privacy, individuals are afforded the ultimate "freedom of choice," or autonomy (Proshansky et al., 1970).

A study of university students revealed a psychological distinction between privacy and territory, such that privacy exists in a social space (as in physical and auditory isolation), while territory implies ownership over a physical space (as in the home). Participants in the study additionally indicated a preference for variations of privacy and territory, depending on the activity in which they were engaged. When studying, for example, most participants preferred privacy and territory, but when socially drinking, most participants preferred no privacy and no territory (Edney & Buda, 1976). Privacy as social isolation can be afforded by the environment through environmental characteristics like soundproofing and visual barriers (Edney & Buda, 1976).

In the context of health environments, territoriality may be more difficult to achieve than privacy, as a sense of personal territory requires an individual to spend substantive time within a space to form attachment (Edney, 1974). It additionally requires that an occupant have the ability to mark or manipulate their space in line with their individual preferences and personality. In a highly-regulated clinical setting, patients may not be afforded the time or flexibility to form a sense of territory.

Current Study

Through previous interviews and qualitative survey responses (Chapters 2 and 3), adolescents and young adults with cancer have described the importance of certain environmental characteristics in the treatment environment, specifically those affording choice and control.

In Chapter 3, the researcher identified four environmental characteristics rated most inadequate by AYA participants (ratings of inadequacy were determined as the

difference between participant ratings of importance and effectiveness): *outdoor space*, *patient-only lounge*, *meditative space*, and *patient rooms*.

Because of the lack of facilities and existing literature to support the design of these facilities, this study will assess these four environmental characteristics on their affordance of choice and control. The importance of receiving AYA feedback on design guidelines is supported in existing literature – a recent Spanish study revealed substantial differences in the design preferences described by hospitalized adolescents (ages 14 – 17), parents, and clinical staff (Ullán et al., 2012).

As participatory design is concerned with matters of description and prefers "purpose statements" to traditional research questions (Spinuzzi, 2005), a series of descriptive hypotheses is most appropriate. *Hypothesis #1* states participants will prioritize private bedrooms, private bathrooms, small number of patients per unit, visitor beds in patient rooms, meditative space, and personalizable rooms over other environmental characteristics, as these were most associated with salient issues of choice and control in Chapter 3.

Through focus group discussions supported by photo evaluations, *Hypothesis #2* states participants will prefer photos (and specific environmental characteristics within those photos) depicting the achievement of privacy and control.

Methods

The focus groups followed Spinnuzi's three-stage iterative participatory design methodology (2005):

- Stage 1: *Initial exploration*. Researchers become familiar with the users and the design challenge. This stage generally occurs before substantial researcher-

user interaction and involves less intrusive research techniques, like observations and interviews. For the purpose of this study, the exploration phase has been satisfied by the results from Studies 1 and 2.

- Stage 2: *Discovery processes*. The focus groups began at this stage, during which the users and researchers discuss priorities, goals, and values for the design. In the current study, a set of semi-structured interviews, a scenario-building exercise, and a space prioritization activity were included in the discovery stage.
- Stage 3: *Prototyping*. After discovery, users and researchers work together to create artifacts to communicate design preferences – in this case, as the focus groups were conducted online, participants evaluated photo sets as a mechanism of communicating design goals and preferences.

Participants

Participants were eligible for the study if they were treated for cancer between the ages of 15 to 39, identifying as any gender, and have received (or currently receiving) treatment for a cancer diagnosis. Exclusion criteria for participants included co-morbid diagnoses, any major developmental disorders, receiving end-of-life care, and/or diagnosed less than three months' prior (adapted from Ewing, King, & Smith, 2009). Participants were recruited through outreach by various AYA cancer organizations, including the Ulman Fund, First Descents, and Lacuna Loft. These organizations shared the study information on various social media channels and listservs.

At the time of the focus groups, all participants were categorized as late young

adults between the ages of 25-39, though three participants were first diagnosed prior to age 25 during adolescence and early young adulthood. One participant was 43 at the time of the study, although she had been diagnosed prior to age 39. Participants were treated at inpatient facilities and outpatient facilities across the US, ranging from large academic health systems to private specialty clinics. Most patients had experience with both inpatient and outpatient facilities. None of the participants recalled having access to a specialized AYA program or AYA resources at their treatment facility. Of the participants that provided a diagnosis, breast cancer and Hodgkin's lymphoma were most commonly reported (see Table 4.1). In AYA patients, breast cancer is the most commonly diagnosed cancer type, accounting for approximately 20% of new cases each year. Hodgkin's lymphoma accounts for only 2.5% of new cases (Fidler et al., 2017).

Table 4.1

Participant Profiles by Demographic

#	*Gender*	*Age at study*	*Age at first diagnosis*	*Age when treatments completed*	*Type of cancer*
1	Female	43	38	*	Breast
2	Female	28	20	21	Leukemia
3	Male	35	27	27	Testicular
4	Female	39	26	37	Breast
5	Female	31	28	28	Hodgkin's lymphoma
6	Female	26	17	18	Hodgkin's lymphoma
7	Female	34	30	*	Non-Hodgkin's lymphoma
8	Female	24	17	18	Non-Hodgkin's lymphoma
9	Female	37	25	25	Hodgkin's lymphoma
10	Female	33	30	32	Breast
11	Male	33	30	*	Leukemia
12	Male	33	29	30	Melanoma
13	Male	31	26	26	Testicular

** treatments ongoing*

Procedure

The focus groups were convened online through Zoom – a video conferencing platform that allows for both group conversations and individual breakout sessions. The focus groups were approximately 60 minutes. Online participants were encouraged to enable both audio and video, but only required to enable audio. The researcher (who served as the focus group proctor) was visible via video to online participants.

Each focus group followed the same procedure:

1. Review consent form and study goals
2. Introduction to virtual environment
3. Pre-set questions; scenario building
4. Space priorities activity; discussion
5. Environmental preferences activity; discussion
6. Debrief

After introducing the study and reviewing the consent form provided previously via email, participants were instructed to complete a short demographic survey through Qualtrics. Following the survey, participants engaged in interviews and scenario-building as a group for 15-20 minutes. The questions and scenarios were organized into five sections: identity, independence, relationships with family and friends, intimate relationships, and future achievement (based on the goals of adolescence and young adulthood) (see Table 4.2).

To evaluate the results of the interviews, audio from the focus groups was transcribed by the researcher using Trint, an online transcription software. Interviews

were transcribed verbatim and transcripts were imported into Atlas.ti for qualitative analysis

Table 4.2

Interview Questions for Scenario-Building

Identity
1. You are staying at a hospital for a few nights. Do you do anything to change the room?
Independence
1. Did you have to be accompanied when you were at the hospital? 2. You are at hospital and you're hungry. What do you do?
Relationships with Family and Friends
1. Where did you socialize most often? With whom did you socialize? 2. How do you think being able to talk on the phone or text message with friends has changed the patient experience? 3. You are in inpatient treatment and you want your parents to stay overnight. What happens? What about a friend?
Intimate Relationships
1. Did you or your significant other have any concerns before they visited you? 2. Your significant other comes to visit you in the hospital. Where do they stay?
Future Achievement
1. You're still in school or employed. You're trying to finish up classwork or work from your job. When you're in treatment, how do you get your work done? 2. Do patients receive any tutoring?

Following the group interview, participants were asked to complete an individual space priorities task. The task took approximately three minutes, followed by a five-minute group discussion. Participants were provided with the link to a sorting task using the OptimalWorkshop online platform (see Appendix C). Participants were asked to sort the environmental features into three categories: Must Have (most important), Should Have, and Could Have (least important). The feature

inventory was previously constructed and evaluated in Study 2 (see Table 4.3). They were provided with the following instructions:

> *Imagine you have a limited budget and you are building a new AYA facility for patients your age. We'd like you to sort the following items into groups. A "Must Have" item is one that you would definitely include in your new facility. A "Should Have" item is one that you would recommend. A "Could Have" item is one that you would only add if you had enough remaining funds. There is no right or wrong answer, just do what comes naturally. There should be a similar number of items in each group.*

Table 4.3

Facility Feature Inventory for Prioritization Task

Facility Features
Outdoor space
Patient-only lounge
Motivational message board
Access to kitchen
Meditative space
Classroom
Daylight
Internet and computer resources
Family-patient lounge
Moveable seating
Artwork
Small number of patients per unit
Recreation (TV, games)
Patient Room Features
Visitor beds in patient rooms
Personalizable rooms

Personal desk space
Private bathrooms
Private bedrooms
Personal closet space
Clinical Features
Therapy area (PT, OT, art, music)
Staff-patient consulting area

Following the space priorities activity, participants completed an individual environmental preference task. The task took approximately three minutes, followed by a five-minute group discussion. Using the previously developed photo pool, participants were shown a set of nine photos representing one environmental characteristic (outdoor space, for example). Participants were provided with the following instructions: "The following photos are examples of outdoor space. If you were designing a new cancer facility for patients your age, select three photos that you would use for inspiration." The photo sets were presented in color on a 1000x1000px grid and clicked to select their three choices (see Appendix D). After individually selecting three photos, participants were given five minutes to discuss their selections as a group. Participants repeated this process three more times, evaluating photos sets representing outdoor space, patient-only lounges, patient rooms, and meditative space.

Tools. To create the photo set, six judges evaluated an initial pool of 100 photos, resulting in a final set of 36 photos (nine photos for each of four environmental characteristics). The initial photo pool was constructed from images obtained through Google Image searches performed by the researcher. Twenty-five photos were selected for each of four environmental characteristics based on the

photos' representation of several environmental qualities: privacy, social interaction, autonomy, independence, coherence, and support. The initial photo pool represented a diverse sample of non-clinical environments, including coffee shops, cafeterias, living rooms, and workplaces. Clinical environments were specifically excluded to reduce the bias associated with negative experiences of cancer survivors.

Graduate students at Cornell University in the Department of Design and Environmental Analysis served as judges based on their training in design, architecture, social science, and human-environment relations. Judges' ages ranged from 24 to 41 years (median age = 28.5). Two groups of three judges each were presented with 50 photos from the initial pool, ensuring each photo was evaluated by three judges. Each photo was presented consecutively using PowerPoint on a large projector display. Judges were given 60 seconds per photo to evaluate the images using the following checklist adapted from McCoy & Evans' (2002) methodology for photo set development. This checklist included ratings for the four environmental qualities previously rated most important by AYA participants: *autonomy over decisions*, *privacy*, *control over social interaction*, and *independence.* It also included two additional qualities from McCoy & Evans' original checklist – support and coherence:

Table 4.4

Checklist for Rating Environmental Qualities in Photo Development

Privacy
0. Does not apply. 1. This place would give me a sense of personal space. 2. I would come here to be away from others. 3. I could come here to feel better.
Interaction
0. Does not apply. 1. This would give me an opportunity to talk to people. 2. I would come here to interact with others. 3. I could come here to receive social support from others.
Independence
0. Does not apply. 1. This place would give me a sense of independence. 2. I would feel open to new experiences here. 3. I could do anything I want to here.
Support
0. Does not apply. 1. This place would encourage me. 2. I would feel competent here. 3. I could do many things here.
Coherence
0. Does not apply. 1. This place makes sense. 2. I would feel at home here. 3. I would feel "together" here.
Autonomy
0. Does not apply 1. This place limits me. 2. I would feel required to follow the rules here. 3. This place would require me to conform to rigid standards.

The final photo set comprised nine images each of four environmental characteristics, for a total of 36 images. The images with the highest mean scores and lowest standard deviations (most representative) and with the lowest mean scores and lowest standard deviations (least representative) for each of the six environmental qualities were selected.

Results

Space Prioritization

Hypothesis #1 stated participants would prioritize private bedrooms, private bathrooms, small number of patients per unit, visitor beds in patient rooms, meditative space, and personalizable rooms over other environmental characteristics, as the aforementioned were most associated with salient issues of choice and control in Chapter 3. This hypothesis was partially supported – the majority of participants considered private bathrooms, private bedrooms, and visitor beds in patient rooms as *Must Have* characteristics. Small number of patients per unit, meditative space, and personalizable rooms were considered *Should Have* characteristics, or those that should be considered if a budget allowed (see Table 4.5).

Supporting the consensus among the *Must-Have* characteristics, one participant said "Some of this stuff seems non-negotiable. Like there's not really a question about whether there should be private bedrooms or bathrooms… and you need to have a place for visitors to sleep in the room."

Table 4.5

Prioritization Placement Matrix by Percentage of Participants

	Must Have	*Should Have*	*Could Have*
Internet and computer resources	100%	0%	0%
Daylight	92%	0%	8%
Access to kitchen	83%	17%	0%
Private bathrooms	83%	8%	8%
Private bedrooms	75%	25%	0%
Recreation (TV, games)	67%	25%	8%
Visitor beds in patient rooms	67%	17%	17%
Family-patient lounge	50%	33%	17%
Therapy area (PT, OT, art, music)	50%	42%	8%
Moveable seating	33%	33%	33%
Personal closet space	33%	33%	33%
Small number of patients per unit	25%	67%	8%
Staff-patient consulting area	8%	67%	25%
Artwork	17%	58%	25%
Meditative space	25%	58%	17%
Outdoor space	33%	58%	8%
Personal desk space	8%	50%	42%
Personalizable rooms	33%	42%	25%
Classroom	0%	8%	92%
Motivational message board	17%	33%	50%
Patient-only lounge	8%	42%	50%

Photo Evaluations

Hypothesis #2 stated participants would prefer photos (and specific environmental characteristics within those photos) depicting the achievement of privacy and control. These results were also partially supported within each of the photo evaluation sets.

Outdoor space. When selecting three photos for design inspiration of a new AYA facility, 100% of participants chose #5, followed by 50% of participants choosing #3 and 42% of participants choosing #8. No participants selected #7 and only one participant each selected #1 or #9.

Figure 4.2. Photo set presented to participants for evaluation of outdoor spaces.

When asked as a group to discuss the photos that stood out positively or negatively, participants overwhelmingly mentioned the colors and seating in photo #5.

Hypothesis #2 was partially supported in the evaluation of the outdoor spaces. Experts unanimously rated photo #5 as most affording privacy ($M = 3.00$, $SD = 0.00$), with the other popular photos #3 and #8 ranked in second and third place, respectively. Photo #5 was rated as unrestrictive of personal autonomy ($M = 0.67$, $SD = 0.82$) and tied for ranking second place in affording independence ($M = 1.83$, $SD = 0.41$). Of the other popular photos, expert ratings of photo #8 indicated it ranked second in autonomy and independence.

Contrary to the hypothesis, photo #1 was only selected by one participant but was rated most highly by experts on independence ($M = 2.17$, $SD = 0.75$) and

autonomy (M = 0.50, SD = 0.55).

Lounge areas. Lounge areas were also addressed (see Figure 4.3). Sixty-seven percent of participants chose #1, followed by 58% of participants choosing #7 and 50% of participants choosing #6. Only one participant selected #5.

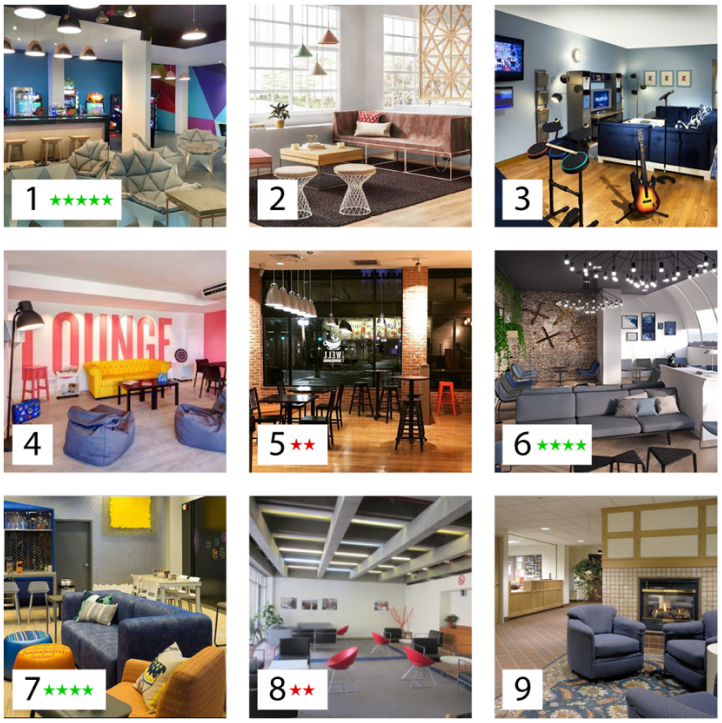


Figure 4.3. Photo set presented to participants for evaluation of lounge areas.

When prompted to discuss the options that stood out positively, participants primarily mentioned the seating in #1 and #7. Several participants appreciated the industrial-look exposed brick in both #5 and #6, but preferred the seating in #6, suggesting the barstool seating in #5 was impractical and uncomfortable in a treatment environment.

Hypothesis #2 was supported in the evaluation of the lounge areas. Experts rated photo #6 as most affording privacy (M = 2.00, SD = 1.26), with the other popular

photos #1 and #7 tied for ranking in the top three for privacy. Though photo #3 was rated as the least restrictive of personal autonomy ($M = 0.67$, $SD = 0.82$) and most supportive of independence ($M = 2.33$, $SD = 0.52$), photos #1, #6 and #7 were also tied for ranking in the top three for autonomy and independence.

Only selected by one participant, photo #8 was rated by the experts as least affording privacy ($M = 0.33$, $SD = 0.52$) and the most restrictive of personal autonomy ($M = 2.00$, $SD = 0.63$) and independence ($M = 0.83$, $SD = 0.75$).

Meditation spaces. Regarding meditation spaces (see Figure 4.4), 83% of participants chose #2, followed by 50% of participants choosing #3 and 42% of participants choosing #5. No participants selected #9.

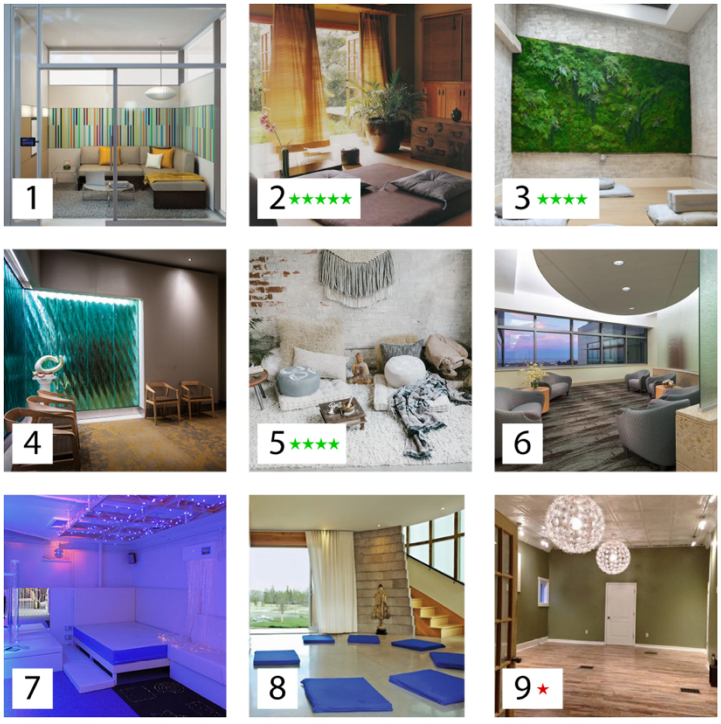


Figure 4.4. Photo set presented to participants for evaluation of meditation areas.

Hypothesis #2 was partially supported in the evaluation of the meditation spaces. Experts rated photo #2 as highly affording privacy ($M = 2.50$, $SD = 0.84$), with

the other popular photos #3 and #5 tied for ranking in the top three for privacy. Photo #2 was rated as unrestrictive of personal autonomy ($M = 0.83$, $SD = 0.98$) and most supportive of independence ($M = 2.00$, $SD = 0.00$). Contrary to the hypothesis, though photo #5 was popular among participants, it was rated highly restrictive of personal autonomy ($M = 0.50$, $SD = 0.55$).

Not selected by any participants, photo #9 was rated by the experts as least affording privacy ($M = 1.00$, $SD = 1.10$) and among the most restrictive of personal autonomy ($M = 1.00$, $SD = 0.89$).

Patient rooms. Seventy-five percent of participants chose #5, followed by 58% of participants choosing #9 and 50% of participants choosing #6. Only one participant selected #7.

Figure 4.5. Photo set presented to participants for evaluation of patient rooms.

Hypothesis #2 was partially supported in the evaluation of the patient rooms. None of the rooms were rated highly on privacy, though experts rated photo #5 as among the top two from this set ($M = 1.67$, $SD = 0.82$), with photo #9 tied for ranking in the top three for privacy. Photo #5 was rated as unrestrictive of personal autonomy ($M = 0.83$, $SD = 0.98$) and most supportive of independence ($M = 2.00$, $SD = 0.00$).

Contrary to the hypothesis, though photo #2 was not among the most popular AYA selections, it was rated by experts as affording the most privacy ($M = 1.83$, $SD = 0.75$) and the most supportive of independence ($M = 2.00$, $SD = 1.10$).

Only selected by one participant, photo #7 was rated by the experts as among the least affording privacy ($M = 1.33$, $SD = 0.52$) and among the least affording independence ($M = 1.17$, $SD = 0.41$).

Just as the expert ratings for patient rooms were similar and hovered around neutral, so too did the qualitative participant responses to the rooms. Several participants reported difficulty choosing between the options, with one participant explicitly stating, “I felt neutral about all of these.”

Discussion

Hypotheses #1 and #2 were both partially supported, suggesting the importance of privacy, autonomy, and independence in the design of treatment environments for AYAs. There were notable deviations from the hypotheses, however, indicating other factors may be contributing to AYA preferences. Several photos were rated by experts as very low on privacy, independence, and/or autonomy – yet, they were among the popular choices by AYAs. The affordance of choice and control certainly contributed to AYA preferences, but other environmental qualities could be more salient in the decision-making process, including positive distraction, comfort, and the inclusion of family members and caregivers.

Choice and Control

Results of the prioritization task (Table 4.5) echo the surprising results from Chapter 3, such that patient-only lounges were considered low-priority. Previous research (and results from this dissertation) suggest opportunities for peer interaction among AYAs with cancer are limited but highly desired (Cheung & Zebrack, 2017; Kent et al., 2013; Warner et al., 2016; Zebrack, Bleyer, Albritton, Medearis, & Tang, 2006). This is supported by the increasing participation in social survivorship groups, like the Ulman Fund's Cancer to 5K, CancerCon, First Descents, True North Treks, etc. The disinterest in patient lounges as an avenue for peer connections may related to issues of choice and control, as discussed in Chapter 3.

Peer connections among AYAs seem to occur most frequently during survivorship (outside of the treatment environment), though peer connections during diagnosis and treatment could be highly beneficial, particularly to afford the

opportunity for seeking and providing information, as noted in Chapter 2.

The balance between social interaction and privacy supported the inclusion of a staff-patient consulting area – one participant said she had a private room during her inpatient experience, but "if I was being treated outpatient, it's important to have somewhere you can go and you can talk to your doctors in confidence and not be afraid that other people are overhearing you."

Issues of choice and control extended to the discussion of daylight and outdoor spaces in the focus groups. One participant did not rank daylight as a *Must Have* because he "just wanted calm and dark and feeling like I was going to sleep. So, I kind of didn't want daylight." One participant responded, saying "That's kind of how I felt about the outdoor space. I was treated in Minnesota in the middle of winter… but like we were not going to be going out there." A desire to control daylight exposure was physiologically motivated, as well – participants noted the negative interaction between many cancer treatments and sunlight. One participant said "I liked how it felt like a very enclosed green space, partly because of the shade. My medication made me super sensitive to that." Although participants didn't like the tables in outdoor photo #6 (left), they noted the umbrellas – "I like that it would be a nice place to sit and not be under the sun."

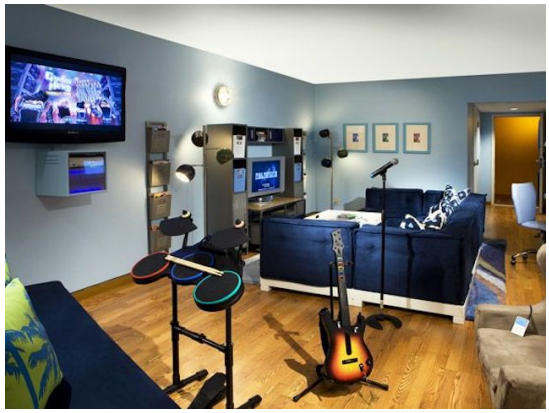
Positive Distraction

Many of the positive responses from participants were related to recreation

opportunities. When discussing photos of outdoor space, the majority of participants selected photo #3 (right) – in part because it provided a discrete activity – "I'd like to go walk outside when I could. Little mazes [or some] walking space would be nice."

Color also contributed to positive distraction. In reference to the colors in photo #5 (left) during the discussion of outdoor space, a participant said "I kind of got a tropical vibe from it. And I love a tropical vacation, so when you're in such a bad space, to kind of feel like you're in a tropical space helps your mood a little bit." Another participant noted, "It just looks so inviting with the pillows, it's colorful." Preference for these bright, saturated colors has mixed support in existing literature. In assessing artwork, patients preferred representational images with subdued, natural colors to brighter, abstract images, perhaps because viewing abstract images provides patients with less sensory control (McCuskey Shepley, 2006; Ulrich, 1991). Results of a design workshop involving Danish young adults with cancer (ages 15 – 29) indicated preferences for pale colors over brighter schemes (Boisen et al., 2017). However, in a study of younger adolescent hospital patients ages 12 – 14, participants preferred brighter color schemes to subdued color schemes (Blumberg & Devlin, 2006).

Even though many participants described themselves as "not gamers," they still responded positively to lounge photo #3 (right) because, as one participant said, "I do think it's good to have stuff to do. That's the one thing I'm really jealous about at the children's hospital – there's always games and video games and a Wii and I just think that would have been helpful to have something to do."



Included in the meditation space set was a sensory room (photo #7, left) and although participants had mixed feelings about the lighting and stimulation, many participants agreed that it may be a good distraction, especially for patients with special needs.

Comfort

Though seating was easily the most frequently discussed topic, "moveable seating" wasn't prioritized among participants. This is likely because rearrangement was less important than comfort. When asked which characteristics were immediately put in the *Could-Have* column, one participant said "I put moveable seating. I mean, it would be nice, but I don't think it makes or breaks it. Comfortable seating would be more important to me."

The inclusion of comfortable furniture could "make or break" a participant's evaluation of a photo across any of the categories. When discussing a photo of the meditation spaces, a participant said, "I liked [Photo #4, left] but I didn't like the chairs," so she did not select it. When asked why they selected certain photos, one participant said, "I tend to go to the one that had the comfiest looking seating." Another group member agreed, saying "Anything that had the comfortable seating." Another participant had a similar reaction in the mediation space discussion, saying "I was immediately drawn to [Photo #2, right] just because it looked the comfiest." Having to sit directly on the ground (without soft, supporting material) was a highly negative characteristic in the meditation spaces – "I don't like sitting on the floor because my legs fall asleep immediately from treatments." Similarly, images featuring hardwood floors were often not selected.

A European study of over 300 AYAs (ages 13 – 49 years) emphasizes the importance of comfortable furniture. When asked about age-specific elements in their environment, participants prioritized age-appropriate decoration and comfortable furniture (Jones, Pini, Morgan, Birk, & Stark, 2017). A survey of adolescents (ages 13

– 18) in a drug/alcohol rehabilitation facility indicated comfortable furniture as an important characteristic contributing to patient satisfaction (Potthoff, 1995).

Inclusion of Caregivers and Family

In the prioritization task and the accompanying discussion, participants frequently discussed the value of family-oriented elements. The family-patient lounge was considered both an important social resource for the patient and as an opportunity for respite for family members. Support from family and friends is considered equally, if not more, important than peer connections in several AYA studies (Zebrack et al., 2006; Zebrack, Mills, & Weitzman, 2007).

One participant noted, "I [had] the family-patient lounge as a must-have. Not even for myself, but my mom was my primary caregiver and I feel like that was really important for her to have a place where she could go and kind of take a break." Participants mentioned similar value for the meditative space – "I think the meditative space was a nice idea because it could be for patients or also like your family member that was staying with you." In the patient rooms, participants noted "I put the visitor beds as being important just because I know that my mom would stay with me sometimes but the only have this uncomfortable chair for her." In the most popular photo of the outdoor spaces (see right), a participant said, "I liked the one right in the middle – it just seemed like a place that you could have lunch with your family outside."

Future Research

As a methodology, Spinuzzi's (2005) participatory design encourages an iterative approach – one in which users and researchers repeat the discovery and prototyping stages to synchronize their goals and design proposals. While proposing a finite design would be challenging in the current study, given the broad nature of the research questions, the results of this study could be extended in future research through further iteration. Evaluating a mock-up, for example, would be a valuable next step in the participatory design process toward the goal of AYA-inclusive cancer facilities.

Limitations

The participant sample consisted of mostly "older AYAs" and was predominately female. Even with a recruiting effort targeted to male participants, it was difficult to obtain a balanced sample of participants. It is possible the preferences described by participants would be different with a younger sample or with a greater number of male participants. In particular, there may be a different perspective on the value of family-oriented spaces, as many of the older AYAs had fiancés, spouses, and young children.

The choice to proceed with online focus groups was motivated by a desire to include participants from across the United States, rather than participants siloed in one geographic region (which would have occurred if the focus groups were conducted with a regional cancer support group, for example). While this decision allowed for a broader range of facility experiences, the online format had its limitations. Although most participants shared their video feed, it was still difficult to

interpret non-verbal cues as a group, leading to substantial pauses and lapses. Participants were often delayed in speaking, waiting to see if others would respond. Even if participants agreed with another participant's comment, they often didn't voice their consensus verbally, because it would disrupt the audio feed from a speaking participant.

Adapting participatory design to an online format could be a potentially valuable tool for accessing vulnerable populations and collecting geographically diverse perspectives. Future research comparing results from online and in-person focus groups would be beneficial in the development of this new tool.

Conclusion

Providing AYAs an opportunity to participate in the design process meaningfully extended the results of Chapters 2 and 3. In the prioritization task and photo evaluations, participants responded most positively to characteristics and environments providing privacy, independence, and autonomy. The provision of choice and control was not, however, the only salient factor in participants' evaluation of a space. Consideration for positive distraction, comfort, and caregiver inclusion also contributed to the positive evaluation of an environment. Though there was an interest in creating dedicated patient areas (meditation rooms, patient-only lounge, etc.), participants more frequently discussed smaller-scale changes, like comfortable seating, adjustable lighting, and furniture for overnight guests. These results should be encouraging for those in practice, as many AYA preferences expressed in this study could be satisfied within a small budget or a small footprint.

References

Altman, I. (1975). *The Environment and Social Behavior: Privacy, Personal Space, Territory, and Crowding*. Monterey, CA: Brooks/Cole.

Blumberg, R., & Devlin, A. S. (2006). Design issues in hospitals: The adolescent client. *Environment and Behavior*, *38*(3), 293–317.

Boisen, K. A., Boisen, A., Thomsen, S. L., Matthiesen, S. M., Hjerming, M., & Hertz, P. G. (2017). Hacking the hospital environment: young adults designing youth-friendly hospital rooms together with young people with cancer experiences. *International Journal of Adolescent Medicine and Health*, *29*(4). https://doi.org/10.1515/ijamh-2015-0072

Cheung, C. K., & Zebrack, B. (2017). What do adolescents and young adults want from cancer resources? Insights from a Delphi panel of AYA patients. *Supportive Care in Cancer*, *25*(1), 119–126. https://doi.org/10.1007/s00520-016-3396-7

Davies, S., Laker, S., & Ellis, L. (1997). Promoting autonomy and independence for older people within nursing practice: A literature review. *Journal of Advanced Nursing*, *26*(2), 408–417. https://doi.org/10.1046/j.1365-2648.1997.1997026408.x

Edney, J. J. (1974). Human territoriality. *Psychological Bulletin*, *81*(12), 959–975. https://doi.org/10.1037/h0037444

Edney, J. J., & Buda, M. A. (1976). Distinguishing territoriality and privacy: Two studies. *Human Ecology*, *4*(4), 283–296. Retrieved from JSTOR.

Ewing, J. E., King, M. T., & Smith, N. F. (2009). Validation of modified forms of the

PedsQL generic core scales and cancer module scales for adolescents and young adults (AYA) with cancer or a blood disorder. *Quality of Life Research*, *18*(2), 231–244. https://doi.org/10.1007/s11136-008-9424-4

Fidler, M. M., Gupta, S., Soerjomataram, I., Ferlay, J., Steliarova-Foucher, E., & Bray, F. (2017). Cancer incidence and mortality among young adults aged 20–39 years worldwide in 2012: a population-based study. *The Lancet Oncology*, *18*(12), 1579–1589. https://doi.org/10.1016/S1470-2045(17)30677-0

Hill, J. P. (1983). Early adolescence: A research agenda. *The Journal of Early Adolescence*, *3*(1–2), 1–21. https://doi.org/10.1177/027243168331002

Horowitz, A., Silverstone, B. M., & Reinhardt, J. P. (1991). A conceptual and empirical exploration of personal autonomy issues within family caregiving relationships. *The Gerontologist*, *31*(1), 23–31. https://doi.org/10.1093/geront/31.1.23

Jones, L. J. W., Pini, S. A., Morgan, S. J., Birk, G. K., & Stark, D. P. (2017). How do teenagers and young adults with cancer experience their care? A European survey. *Journal of Adolescent and Young Adult Oncology*, *6*(1), 102–110. https://doi.org/10.1089/jayao.2016.0011

Kent, E. E., Smith, A. W., Keegan, T. H. M., Lynch, C. F., Wu, X.-C., Hamilton, A. S., … the AYA HOPE Study Group, Linda C. (2013). Talking about cancer and meeting peer survivors: Social information needs of adolescents and young adults diagnosed with cancer. *Journal of Adolescent and Young Adult Oncology*, *2*(2), 44–52. https://doi.org/10.1089/jayao.2012.0029

Lawton, M. P. (1985). The elderly in context: Perspectives from environmental

psychology and gerontology. *Environment and Behavior*, *17*(4), 501–519. https://doi.org/10.1177/0013916585174005

McCoy, J. M., & Evans, G. W. (2002). The Potential Role of the Physical Environment in Fostering Creativity. *Creativity Research Journal*, *14*(3–4), 409–426. https://doi.org/10.1207/S15326934CRJ1434_11

McCuskey Shepley, M. (2006). The role of positive distraction in neonatal intensive care unit settings. *Journal of Perinatology*, *26*(S3), S34–S37. https://doi.org/10.1038/sj.jp.7211584

Pastalan, L. A. (1970). Privacy as an expression of human territoriality. In L. A. Pastalan & D. H. Carson (Eds.), *Spatial Behavior of Older People*. Ann Arbor: University of Michigan Press.

Potthoff, J. K. (1995). Adolescent satisfaction with drug/alcohol treatment facilities: Design implications. *Journal of Alcohol and Drug Education*, *41*(1), 62–73.

Proshansky, H. H., Ittleson, W. H., & Rivlin, L. G. (1970). Freedom of choice and behavior in a physical setting. In H. H. Proshansky, W. H. Ittleson, & L. G. Rivlin (Eds.), *Environmental Psychology*. New York: Holt, Rinehart & Winston.

Spinuzzi, C. (2005). The methodology of participatory design. *Technical Communication*, *52*(2), 163–174.

Teel, C., Dunn, W., Jackson, S. T., & Duncan, P. (1997). The role of the environment in fostering independence: Conceptual and methodological issues in developing an instrument. *Topics in Stroke Rehabilitation*, *4*(1), 28–40. https://doi.org/10.1310/9MYM-4FB4-9Y1A-9MR2

Ullán, A. M., Belver, M. H., Fernández, E., Serrano, I., Delgado, J., & Herrero, C. (2012). Hospital designs for patients of different ages: Preferences of hospitalized adolescents, nonhospitalized adolescents, parents, and clinical staff. *Environment and Behavior*, *44*(5), 668–694. https://doi.org/10.1177/0013916511403802

Ulrich, R. S. (1991). Effects of interior design on wellness: Theory and recent scientific research. *Journal of Health Care Interior Design*, *3*(1), 97–109.

Warner, E. L., Kent, E. E., Trevino, K. M., Parsons, H. M., Zebrack, B. J., & Kirchhoff, A. C. (2016). Social well-being among adolescents and young adults with cancer: A systematic review. *Cancer*, *122*(7), 1029–1037. https://doi.org/10.1002/cncr.29866

Zebrack, B., Bleyer, A., Albritton, K., Medearis, S., & Tang, J. (2006). Assessing the health care needs of adolescent and young adult cancer patients and survivors. *Cancer*, *107*(12), 2915–2923. https://doi.org/10.1002/cncr.22338

Zebrack, B. J., Mills, J., & Weitzman, T. S. (2007). Health and supportive care needs of young adult cancer patients and survivors. *Journal of Cancer Survivorship*, *1*(2), 137–145. https://doi.org/10.1007/s11764-007-0015-0

CHAPTER 5 – DESIGN GUIDELINES

DESIGN GUIDELINES FOR ADOLESCENT AND YOUNG ADULT CANCER TREATMENT ENVIRONMENTS

Over the course of the previous chapters, this doctoral research revealed unmet needs for adolescents and young adults with cancer, including significant inadequacies in the social and built environments for AYAs. In response to the call to research issued by the Adolescent and Young Adult Oncology Progress Review Group, this dissertation contributes:

- An understanding of the psychosocial disruption of cancer during adolescence and young adulthood through a literature review (Chapter 1)
- A phenomenology of the lived experience for AYAs with cancer through a series of interviews (Chapter 2)
- An assessment of the relationship between the built environment, social support, and health-related quality of life through a questionnaire (Chapter 3)
- A description of AYA preferences and needs in the built environment through a set of focus groups (Chapter 4)
- Evidence-based design guidelines for AYA facilities (Chapter 5; current)

Over the last 20 years, practitioners and academics have begun to embrace evidence-based design, or the use of research to inform design decisions in the built environment. The 2018 Facility Guidelines Institute (FGI) *Guidelines for Design and Construction of Hospitals* includes evidence-based guidelines for pediatric and adolescent oncology patient care units, but fails to distinguish between children, adolescents, young adults and the differences in their psychosocial needs.

The following chapter concludes the doctoral dissertation by translating the results of the previous three studies and integrating existing literature in a set of evidence-based design guidelines for AYA oncology environments, filling the gap in the current FGI recommendations. The following guidelines are organized around the four environmental qualities identified in the previous chapter and provide possible design responses (format adapted from Marcus & Sarkissian, 1988):

Design Guidelines and Considerations

Choice and Control

Hierarchy of public, semi-public, semi-private and private space. To ensure a balance between desired and achieved social interaction, facilities should provide transitional spaces within the unit. Transitional spaces, like semi-private cocoon rooms or semi-public lounge areas, allow individuals to control their social interaction and privacy (Al-Homoud & Tassinary, 2004; Ramezani & Hamidi, 2010).

Private rooms. Oncology-specific limitations require private rooms, as suggested in the 2018 FGI recommendations. In addition to reducing infection rates for immune-comprised patients, it is important to provide private rooms and bathrooms for the psychosocial benefit of AYA patients, ensuring a place for refuge and confidentiality (Larsen, Larsen, & Birkelund, 2014). Similarly, restricting the number of patient rooms to ten or less ensures patient control over social interaction on the unit.

Seating choice. Providing moveable seating and numerous seating options allows patients to control their social interaction, even in public or transitional spaces (Pedersen, 1994; Hwang & Yoon, 2009).

Lighting and temperature control. Providing patients with control over ambient room settings contributes to a supportive healthcare environment and has been considered one of the top priorities for cancer patients in infusion centers (Andrade & Devlin, 2015).

Positive Distraction

Internet and computer resources. An essential element for both positive distraction and the provision of social support, Wi-Fi access should be available in all patient areas. Easily accessible outlets and chairs with work surfaces are particularly important in infusion areas, where outpatients may be receiving treatment while working. For immune-compromised patients, especially those in transplant units, internet access provides opportunities for entertainment and social interaction in an enclosed environment.

Age-appropriate entertainment. Entertainment options should be provided, including AYA-appropriate books, movies, video games, and television. The television and video game consoles should be secured to reduce loss of expensive items but should always be accessible to the patient without requiring clinical staff – an important provision for choice and control. In a pediatric unit, care should be taken to ensure entertainment for younger children does not dominate the environment. AYAs often complain of hearing cartoons or children's movies on the television when being treated in a pediatric setting (Peditto, Shepley, Sachs, Mendle, & Burrow, unpublished).

Representational artwork. In assessing artwork, patients preferred representational images with subdued, natural colors to brighter, abstract images,

perhaps because viewing abstract images provides patients with less sensory control (Shepley, 2006; Ulrich, 1991). Results of a design workshop involving Danish young adults with cancer (ages 15 – 29) indicated preferences for pale colors over brighter schemes (Boisen et al., 2017). If possible, in keeping with the Planetree approach, patients should have a range of options to select from to decorate their rooms (Orr, 1993).

Comfort

Comfortable seating. A European study of over 300 AYAs (ages 13 – 49 years) emphasizes the importance of comfortable furniture. When asked about age-specific elements in their environment, participants prioritized age-appropriate decoration and comfortable furniture (Jones, Pini, Morgan, Birk, & Stark, 2017). A survey of adolescents (ages 13 – 18) in a drug/alcohol rehabilitation facility indicated comfortable furniture as an important characteristic contributing to patient satisfaction (Potthoff, 1995).

Home-like furnishings. A sense of comfort can be achieved by including homey features. Feelings of homeyness come from thoughtful selection of furniture, entertainment, colors, textures, and décor (Dowling & Power, 2011). Warm colors, natural materials (stone, wood), handcrafted furniture, and objects of personal significance all contribute to homeyness (McCracken, 1989; Trancik & Evans, 1995). Though furniture selection is often restricted by hygiene guidelines, many health design companies now offer compliant options with a more natural appearance. A space should be made available for personal belongings (photos, artwork, etc.) in the patient room.

It is important to note that many of the guidelines for homeyness result from research involving North American populations. For larger units treating international patients, further research on international preferences should be reviewed.

Provision of Social Support

Distance between functional spaces. Consideration for the placement of practical elements in the treatment environment has been shown to encourage informal social interaction in health environments (Özcan, 2006). Distance between kitchen areas, patient rooms, lounge areas, and clinical areas can increase unscheduled social interaction between patients.

Designated family-patient area. Support from family and friends is considered equally, if not more, important than peer connections in several AYA studies (Zebrack et al., 2006; Zebrack, Mills, & Weitzman, 2007). A space should be provided within the unit (but outside of the patient room) in which families and patients can find respite from the clinical unit. Providing private discussion or consultation areas for families, patients, and staff can also facilitate interaction and the provision of health information (Åstedt-Kurki, Paavilainen, Tammentie, & Paunonen-Ilmonen, 2001).

Cooperative recreation. Because of the barriers to connecting same-age peers within a unit (particularly HIPAA regulations), social connections among AYAs often occur informally while walking in the hall or using a public space (Peditto et al., unpublished). Providing recreation or entertainment options that allow for informal group gatherings can facilitate social relationships within a unit. Multiplayer video games, group seating areas, and television lounges can contribute to informal

opportunities for interaction.

Artifact evidence. Whiteboards, sticky notes, and removable wall décor can all serve as artifact evidence of social support. Designers may consider including a way for patients to leave positive notes for future residents of the same patient room or unit. Family members and friends may also use these tools to communicate social support for a patient.

Family-centered room design. Providing a family area within a patient room can promote family-patient interaction (Choi & Bosch, 2013) and is strongly desired by AYAs (Peditto et al., unpublished). Features of a family-centered room include overnight sleeping accommodations, like recliners or sofa beds, storage for belongings from home, seating for multiple family members, and bathrooms with a door to ensure privacy when multiple people are visiting.

Age-restricted AYA patient area. Previous research (and results from this dissertation) suggest opportunities for peer interaction among AYAs with cancer are limited but highly desired (Cheung & Zebrack, 2017; Kent et al., 2013; Warner et al., 2016; Zebrack, Bleyer, Albritton, Medearis, & Tang, 2006). By providing an age-restricted area for adolescents and young adults, informal social interaction is more likely to occur among age-related peers. This is particularly important in children's hospitals or pediatric units.

Conclusion

Though these recommendations should be strengthened by further research, these design goals are reliable objectives when planning new environments for adolescents and young adults, with many guidelines extending beyond oncology.

Designers and planners should be encouraged by these design guidelines, as many of them are strongly associated with positive outcomes at little expense or loss of square footage. Figures 5.1 – 5.3 provide possible design responses related to these guidelines.

Figure 5.1. Possible design responses for the design of an AYA unit. Floor plan from Fort Worth AYA Oncology Coalition provided by Evelyn Reyers, HKS.

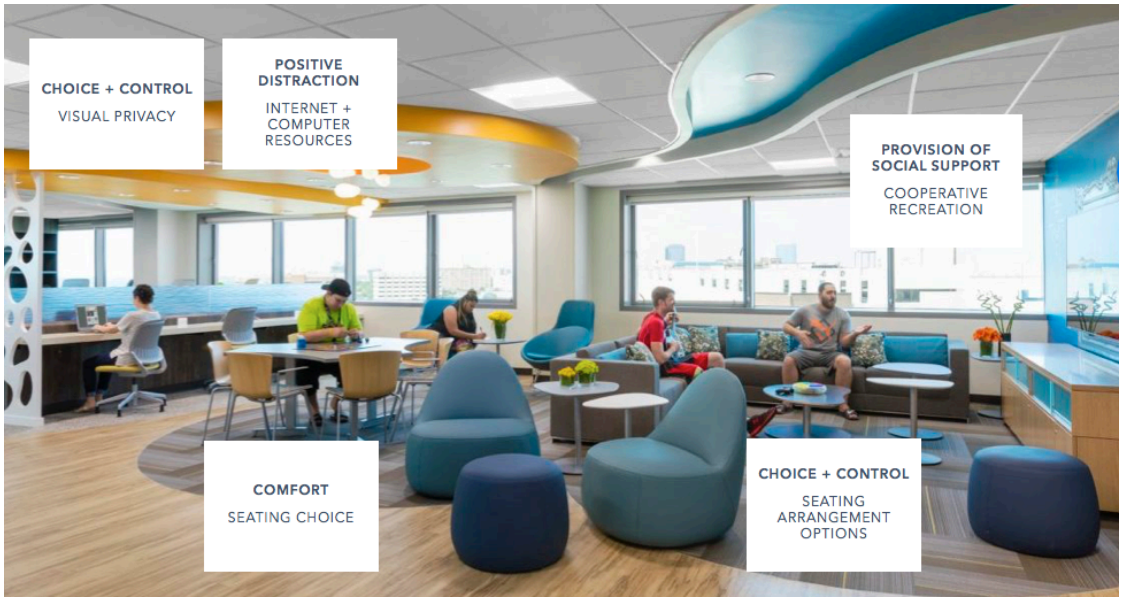


Figure 5.2. Possible design responses for the design of an AYA lounge or recreation area. Image obtained online from Fort Worth AYA Oncology Coalition.

Figure 5.3. Possible design responses for the design of a private AYA patient room.

Researchers have only begun to engage AYAs in the design process – these recommendations will certainly be enhanced in years to come, as AYAs receive the research, funding, and clinical attention uniquely required by their population.

References

Al-Homoud, M., & Tassinary, L. G. (2004). Social interactions at the neighborhood-level as a function of external space enclosure. *Journal of Architectural and Planning Research*.

Andrade, C. C., & Devlin, A. S. (2015). Stress reduction in the hospital room: Applying Ulrich's theory of supportive design. *Journal of Environmental Psychology*, *41*, 125–134. https://doi.org/10.1016/j.jenvp.2014.12.001

Åstedt-Kurki, P., Paavilainen, E., Tammentie, T., & Paunonen-Ilmonen, M. (2001). Interaction between adult patients' family members and nursing staff on a hospital ward. *Scandinavian Journal of Caring Sciences*, *15*(2), 142–150. https://doi.org/10.1046/j.1471-6712.2001.00012.x

Boisen, K. A., Boisen, A., Thomsen, S. L., Matthiesen, S. M., Hjerming, M., & Hertz, P. G. (2017). Hacking the hospital environment: young adults designing youth-friendly hospital rooms together with young people with cancer experiences. *International Journal of Adolescent Medicine and Health*, *29*(4). https://doi.org/10.1515/ijamh-2015-0072

Cheung, C. K., & Zebrack, B. (2017). What do adolescents and young adults want from cancer resources? Insights from a Delphi panel of AYA patients. *Supportive Care in Cancer*, *25*(1), 119–126. https://doi.org/10.1007/s00520-016-3396-7

Choi, Y.-S., & Bosch, S. J. (2013). Environmental affordances: Designing for family presence and involvement in patient care. *HERD: Health Environments Research & Design Journal*, *6*(4), 53–75.

https://doi.org/10.1177/193758671300600404

Dowling, R., & Power, E. (2011). Beyond McMansions and green homes: Thinking household sustainability through materialities of homeyness. In A. Gorman-Murray (Ed.), *Material Geographies of Household Sustainability* (pp. 75–88).

Hwang, J., & Yoon, S.-Y. (2009). Where would you like to sit? Understanding customers' privacy-seeking tendencies and seating behaviors to create effective restaurant environments. *Journal of Foodservice Business Research*, *12*(3), 219–233.

Jones, L. J. W., Pini, S. A., Morgan, S. J., Birk, G. K., & Stark, D. P. (2017). How do teenagers and young adults with cancer experience their care? A European survey. *Journal of Adolescent and Young Adult Oncology*, *6*(1), 102–110. https://doi.org/10.1089/jayao.2016.0011

Kent, E. E., Smith, A. W., Keegan, T. H. M., Lynch, C. F., Wu, X.-C., Hamilton, A. S., … the AYA HOPE Study Group, Linda C. (2013). Talking about cancer and meeting peer survivors: Social information needs of adolescents and young adults diagnosed with cancer. *Journal of Adolescent and Young Adult Oncology*, *2*(2), 44–52. https://doi.org/10.1089/jayao.2012.0029

Larsen, L. S., Larsen, B. H., & Birkelund, R. (2014). A companionship between strangers - the hospital environment as a challenge in patient-patient interaction in oncology wards. *Journal of Advanced Nursing*, *70*(2), 395–404. https://doi.org/10.1111/jan.12204

Marcus, C. C., & Sarkissian, W. (1988). *Housing as if People Mattered: Site Design Guidelines for the Planning of Medium-Density Family Housing* (Vol. 4). Univ

of California Press.

McCracken, G. (1989). Homeyness: A cultural account of one constellation of consumer goods and meanings. In E. C. Hirschman (Ed.), *Interpretive consumer culture* (pp. 168–181). Provo, UT: Association for Consumer Research.

Orr, R. D. (1993). Health Care from the Patients' Perspective. *Journal of Interior Design*, *19*(2), 34-37.

Özcan, H. (2006). Healing design: A holistic approach to social interaction in pediatric intensive care units in the United States and Turkey. *Built Environment*, 18.

Pedersen, D. M. (1994). Privacy preferences and classroom seat selection. *Social Behavior and Personality: An International Journal*, *22*(4), 393–398.

Peditto, K., Shepley, M. M., Sachs, N., Mendle, J., & Burrow, A. (n.d.). Cancer during adolescence and young adulthood: A phenomenological exploration of unmet needs. *Unpublished*.

Potthoff, J. K. (1995). Adolescent satisfaction with drug/alcohol treatment facilities: Design implications. *Journal of Alcohol and Drug Education*, *41*(1), 62–73.

Ramezani, S., & Hamidi, S. (2010). Privacy and Social Interaction in Traditional Towns to Contemporary Urban Design in Iran. *American Journal of Engineering and Applied Sciences*, *3*(3), 501–508. https://doi.org/10.3844/ajeassp.2010.501.508

Shepley, M. (2006). The role of positive distraction in neonatal intensive care unit settings. *Journal of Perinatology*, *26*(S3), S34–S37. https://doi.org/10.1038/sj.jp.7211584

Trancik, A. M., & Evans, G. W. (1995). Spaces fit for children: Competency in the design of daycare center environments. *Children's Environments*, *12*(3), 311–319.

Ulrich, R. S. (1991). Effects of interior design on wellness: Theory and recent scientific research. *Journal of Health Care Interior Design*, *3*(1), 97–109.

Warner, E. L., Kent, E. E., Trevino, K. M., Parsons, H. M., Zebrack, B. J., & Kirchhoff, A. C. (2016). Social well-being among adolescents and young adults with cancer: A systematic review. *Cancer*, *122*(7), 1029–1037. https://doi.org/10.1002/cncr.29866

Zebrack, B., Bleyer, A., Albritton, K., Medearis, S., & Tang, J. (2006). Assessing the health care needs of adolescent and young adult cancer patients and survivors. *Cancer*, *107*(12), 2915–2923. https://doi.org/10.1002/cncr.22338

Zebrack, B. J., Mills, J., & Weitzman, T. S. (2007). Health and supportive care needs of young adult cancer patients and survivors. *Journal of Cancer Survivorship*, *1*(2), 137–145. https://doi.org/10.1007/s11764-007-0015-0

APPENDICES

APPENDIX A

Expert Questionnaire for Survey Development (Chapter 3)

The Impact of Facility Design on Social Support and Interaction for Adolescents with Cancer: Scale Development

This study is led by Kathryn Peditto, who is the Principal Investigator for this study in the Department of Design and Environmental Analysis at Cornell University.

What the study is about
Qualities of the built environment have been previously associated with human health and well-being. As part of a larger study, this pilot questionnaire will identify the qualities of the built environment deemed most important by experts in the healthcare design and planning fields. The final questionnaire will ultimately investigate the relationship between the built environment, perceived social support, and quality of life. The outcomes of this research will provide novel design guidelines to improve social support (and consequently, health-related quality of life) in an adolescent care setting.

What we will ask you to do
I will ask you to complete a brief questionnaire, which will ask generally about the importance and effectiveness of certain features of cancer and/or pediatric care environments. Your responses will not be connected in any way with your name. **The questionnaire will take less than 5 minutes.**

Risks and benefits
We do not anticipate any risks from participating in this research. There are no direct benefits to the participants. Information from this study has the potential to benefit AYA patients in cancer facilities in the future, as the information will inform a set of guidelines with the intent to improve social support and quality of life for patients. There is no payment for taking part in the study.

Privacy/Confidentiality/Data Security
The paper surveys will be transcribed by the researcher and de-identified once the transcriptions are checked for accuracy. If you choose to provide your contact information for future studies, it will not be associated with your survey data in any way. Neither your name nor any other identifying information (such as your job title) will be used in presentations or in written products resulting from the study.

Taking part is voluntary
Your participation is voluntary. You may refuse to participate before the study begins, discontinue at any time, or skip any questions that may make you feel uncomfortable.

If you have questions
The main researcher conducting this study is Kathryn Peditto, a PhD Candidate at Cornell University. Please ask any questions you have now. If you have questions later, you may contact Kathryn at ksp66@cornell.edu or at 410-271-7485. If you have any questions or concerns regarding your rights as a subject in this study, you may contact the Institutional Review Board (IRB) for Human Participants at 607-255-6182 or access their website at http://www.irb.cornell.edu. You may also report your concerns or complaints anonymously through Ethicspoint online at www.hotline.cornell.edu or by calling toll free at 1-866-293-3077. Ethicspoint is an independent organization that serves as a liaison between the University and the person bringing the complaint so that anonymity can be ensured

Statement of Consent: I have read the above information, and have received answers to any questions I asked. I consent to take part in the study.

Participant Signature _____ Date _____

Please indicate your age.

_____

Please indicate your job title.

_____

Do you have work experience with cancer care environments for adolescents or young adults?
Note: You do not need to have experience to continue with the survey.

- ○ Yes, multiple projects
- ○ Yes, one project
- ○ No

Please turn to next page.

The Impact of Facility Design on Social Support and Interaction for Adolescents with Cancer: Scale Development

INPATIENT ENVIRONMENTAL FEATURES

"Environmental features" are defined as specific physical interventions. For example: spaces for indoor therapy, mix of seating, enclosed or open nurse station.

Please evaluate the following features in terms of how **important** you feel they are to adolescent and young adult patients in a cancer care setting.

Facility/Unit Features

	Extremely important	Very important	Moderately important	Slightly important	Not at all important
Recreation (TV, games)	○	○	○	○	○
Access to kitchen	○	○	○	○	○
Internet and computer resources	○	○	○	○	○
Motivational message board	○	○	○	○	○
Moveable seating	○	○	○	○	○
Patient-only lounge	○	○	○	○	○
Family-patient lounge	○	○	○	○	○
Classroom	○	○	○	○	○
Quiet room	○	○	○	○	○
Natural lighting	○	○	○	○	○
Outdoor space	○	○	○	○	○
Small number of patients (1-12 per unit)	○	○	○	○	○

Please turn to next page.

The Impact of Facility Design on Social Support and Interaction for Adolescents with Cancer: Scale Development

Patient Room Features

	Extremely important	Very important	Moderately important	Slightly important	Not at all important
Private bedrooms	○	○	○	○	○
Private bathrooms	○	○	○	○	○
Personal closet space	○	○	○	○	○
Personal desk space	○	○	○	○	○
Personalizable rooms	○	○	○	○	○
Visitor beds in patient rooms	○	○	○	○	○

Clinical Features

	Extremely important	Very important	Moderately important	Slightly important	Not at all important
Staff-patient consulting area	○	○	○	○	○
Enclosed nurse station	○	○	○	○	○
Open nurse station	○	○	○	○	○
Indoor therapy area (PT, OT, art, music)	○	○	○	○	○

Please turn to next page.

What do you think is missing from this list of features?

_____

_____

_____

Please provide the name and location of one or more adolescent and young adult (AYA) cancer facilities that you have found to be especially well-designed.

_____

_____

The survey is complete. Thank you for your time and providing your valuable expertise. Please provide your name and email address if you agree to be contacted in the future regarding this study.

Name: _____

Email: _____

APPENDIX B

Tool for Evaluation of the AYA Cancer Environment (Chapter 3)

The Impact of Facility Design on Social Support and Interaction for Adolescents with Cancer: Questionnaire

This study is led by Kathryn Peditto, who is the Principal Investigator for this study in the Department of Design and Environmental Analysis at Cornell University.

What the study is about
The design of our hospitals can shape our social interaction, improve our quality of life, and help us heal more quickly. The outcomes of this research will help architects and designers build more appropriate cancer care facilities for adolescents and young adults.

What we will ask you to do
You will complete a brief questionnaire, which will ask you to reflect on the design of your cancer treatment environment, your feelings of social support, and your quality of life during treatment. The questionnaire will take approximately 20 minutes.

Risks and benefits
We do not anticipate any risks from participating in this research. Information from this study could benefit patients your age in cancer facilities in the future. All eligible participants will receive a $10 Amazon gift card for their participation. If you would like to receive this incentive, please leave your email address at the end of the survey.

Privacy/Confidentiality/Data Security
If you choose to provide your email address to receive the e-gift card or provide contact information for future studies, it will not be associated with your survey data in any way. We will not include any identifying information if we publish or present the results of this study.

Taking part is voluntary
Your participation is voluntary. You may refuse to participate before the study begins, discontinue at any time, or skip any questions that may make you feel uncomfortable.

If you have questions
The main researcher conducting this study is Kathryn Peditto, a PhD Candidate at Cornell University. Please ask any questions you have now. If you have questions later, you may contact Kathryn at ksp66@cornell.edu or at 410-271-7485. If you have any questions or concerns regarding your rights as a subject in this study, you may contact the Institutional Review Board (IRB) for Human Participants at 607-255-6182 or access their website at http://www.irb.cornell.edu. You may also report your concerns or complaints anonymously through Ethicspoint online at www.hotline.cornell.edu or by calling toll free at 1-866-293-3077. Ethicspoint is an independent organization that serves as a liaison between the University and the person bringing the complaint so that anonymity can be ensured

Statement of Consent: I have read the above information, and have received answers to any questions I asked. I consent to take part in the study.

Participant Signature _____ Date _____

The Impact of Facility Design on Social Support and Interaction for Adolescents with Cancer: Questionnaire

Were you **treated** for cancer between the ages of 15-39?

- ○ Yes
- ○ No – *do not proceed with the survey*

Please indicate the type of cancer that you were first diagnosed with.

_____

What is your current age?

_____

What was your age at diagnosis?

_____

How old were you when your treatments were completed?

_____

Please indicate the type of facilities in which you received treatment for a cancer diagnosis. Please select all that apply.

- ○ Inpatient
- ○ Outpatient
- ○ Emergency
- ○ Other

When did you finish your most recent round of treatment for cancer?

- ○ Within the last six months
- ○ Within the last year
- ○ Within the last two years
- ○ Over two years ago

Did any of your treatment facilities offer an adolescent and young adult (AYA) cancer program or area?

- ○ Yes
- ○ No
- ○ Unsure

Please turn to next page.

The Impact of Facility Design on Social Support and Interaction for Adolescents with Cancer: Questionnaire

What was the name of your outpatient treatment facility? If you received treatment at more than one outpatient facility, choose the one that you spent the most time in.

_____

For outpatient treatment, how many days did you attend this treatment facility? Please estimate the total number of days over the course of your treatment.

_____

What was the name of your inpatient treatment facility? If you received treatment at more than one inpatient facility, choose the one that you spent the most time in.

_____

For inpatient treatment, how many days did you stay at this treatment facility? Please estimate the total number of days over the course of your treatment.

_____

Please turn to next page.

The Impact of Facility Design on Social Support and Interaction for Adolescents with Cancer: Questionnaire

Please evaluate the following qualities in terms of how **important** you feel they are to the support of patients your age in cancer facilities.

	Extremely important	Very important	Moderately important	Slightly important	Not at all important
Opportunity to explore interests and hobbies	○	○	○	○	○
Independence	○	○	○	○	○
Autonomy over decisions	○	○	○	○	○
Autonomy over appearance	○	○	○	○	○
Privacy	○	○	○	○	○
Interaction with outside friends	○	○	○	○	○
Interaction with other patients	○	○	○	○	○
Interaction with parents	○	○	○	○	○
Interaction with significant others	○	○	○	○	○
Physical contact with others	○	○	○	○	○
Opportunity to continue classes or work	○	○	○	○	○
Career exploration	○	○	○	○	○

Please turn to next page.

The Impact of Facility Design on Social Support and Interaction for Adolescents with Cancer: Questionnaire

If you were treated within the last two years, please evaluate how **effectively** the following qualities were incorporated **in your current facility** (or the facility you were most recently treated in).

	Extremely important	Very important	Moderately important	Slightly important	Not at all important
Opportunity to explore interests and hobbies	○	○	○	○	○
Independence	○	○	○	○	○
Autonomy over decisions	○	○	○	○	○
Autonomy over appearance	○	○	○	○	○
Privacy	○	○	○	○	○
Interaction with outside friends	○	○	○	○	○
Interaction with other patients	○	○	○	○	○
Interaction with parents	○	○	○	○	○
Interaction with significant others	○	○	○	○	○
Physical contact with others	○	○	○	○	○
Opportunity to continue classes or work	○	○	○	○	○
Career exploration	○	○	○	○	○

Please turn to next page.

The Impact of Facility Design on Social Support and Interaction for Adolescents with Cancer: Questionnaire

We would like to learn more about your feelings towards cancer facilities. Please rank the following features in terms of their contribution to a **sense of identity** in a cancer facility. Rank the items from 1-5. Write a "1" next to the feature you consider most important and a "5" next to the least.

_____ Private bedrooms

_____ Personal closet space

_____ Personalizable rooms

_____ Personal desk space

_____ Access to recreation (e.g., TV, video games, music)

Please rank the following features in terms of their contribution to **autonomy or independence** in a cancer facility. Rank the items from 1-6. Write a "1" next to the feature you consider most important and a "4" next to the least.

_____ Access to outdoor spaces

_____ Access to kitchens

_____ Private bedrooms

_____ Staff-patient consulting area

Please rank the following features in terms of their contribution to **relationships with friends and family** in a cancer facility. Rank the items from 1-7. Write a "1" next to the feature you consider most important and a "7" next to the least.

_____ Access to recreation (e.g., TV, video games, music)

_____ Access to internet and computer resources (WiFi, etc.)

_____ Patient-only lounge

_____ Family-patient lounge

_____ Small number of patients per unit

_____ Private bedrooms

_____ Visitor beds in patient rooms

Please turn to next page.

The Impact of Facility Design on Social Support and Interaction for Adolescents with Cancer: Questionnaire

Please rank the following features in terms of their contribution to **intimate or sexual relationships** in a cancer facility. Rank the items from 1-5. Write a "1" next to the feature you consider most important and a "5" next to the least.

_____ Access to internet and computer resources (WiFi, etc.)

_____ Patient-only lounge

_____ Family-patient lounge

_____ Private bedrooms

_____ Visitor beds in patient rooms

Please rank the following features in terms of their contribution to **future achievement and success**. Rank the items from 1-5. Write a "1" next to the feature you consider most important and a "5" next to the least.

_____ Access to recreation (e.g., TV, video games, music)

_____ Access to internet and computer resources (WiFi, etc.)

_____ Indoor therapy area (PT, OT, art, music)

_____ Classroom

_____ Personal desk space

Please turn to next page.

The Impact of Facility Design on Social Support and Interaction for Adolescents with Cancer: Questionnaire

Please evaluate the following features in terms of how **important** you feel they are to patients your age in cancer facilities.

Facility/Unit Features

	Extremely important	Very important	Moderately important	Slightly important	Not at all important
Recreation (TV, games)	○	○	○	○	○
Access to kitchen	○	○	○	○	○
Internet and computer resources	○	○	○	○	○
Motivational message board	○	○	○	○	○
Moveable seating	○	○	○	○	○
Patient-only lounge	○	○	○	○	○
Family-patient lounge	○	○	○	○	○
Classroom	○	○	○	○	○
Meditative space	○	○	○	○	○
Natural lighting	○	○	○	○	○
Outdoor space	○	○	○	○	○
Small number of patients (1-12 per unit)	○	○	○	○	○
Artwork	○	○	○	○	○

Please turn to next page.

The Impact of Facility Design on Social Support and Interaction for Adolescents with Cancer: Questionnaire

Patient Room Features

	Extremely important	Very important	Moderately important	Slightly important	Not at all important
Private bedrooms	○	○	○	○	○
Private bathrooms	○	○	○	○	○
Personal closet space	○	○	○	○	○
Personal desk space	○	○	○	○	○
Personalizable rooms	○	○	○	○	○
Visitor beds in patient rooms	○	○	○	○	○
Temperature control	○	○	○	○	○

Clinical Features

	Extremely important	Very important	Moderately important	Slightly important	Not at all important
Staff-patient consulting area	○	○	○	○	○
Indoor therapy area (PT, OT, art, music)	○	○	○	○	○

Please turn to next page.

The Impact of Facility Design on Social Support and Interaction for Adolescents with Cancer: Questionnaire

If you were treated within the last two years, please evaluate how **effectively** the following features were incorporated **in your current facility** (or the facility you were most recently treated in). If you did not have access to one of these features, select "Not effective at all."

Facility/Unit Features

	Extremely effective	Very effective	Moderately effective	Slightly effective	Not effective at all
Recreation (TV, games)	○	○	○	○	○
Access to kitchen	○	○	○	○	○
Internet and computer resources	○	○	○	○	○
Motivational message board	○	○	○	○	○
Moveable seating	○	○	○	○	○
Patient-only lounge	○	○	○	○	○
Family-patient lounge	○	○	○	○	○
Classroom	○	○	○	○	○
Meditative space	○	○	○	○	○
Natural lighting	○	○	○	○	○
Outdoor space	○	○	○	○	○
Small number of patients (1-12 per unit)	○	○	○	○	○
Artwork	○	○	○	○	○

Please turn to next page.

The Impact of Facility Design on Social Support and Interaction for Adolescents with Cancer: Questionnaire

Patient Room Features

	Extremely effective	Very effective	Moderately effective	Slightly effective	Not effective at all
Private bedrooms	○	○	○	○	○
Private bathrooms	○	○	○	○	○
Personal closet space	○	○	○	○	○
Personal desk space	○	○	○	○	○
Personalizable rooms	○	○	○	○	○
Visitor beds in patient rooms	○	○	○	○	○
Temperature control	○	○	○	○	○

Clinical Features

	Extremely effective	Very effective	Moderately effective	Slightly effective	Not effective at all
Staff-patient consulting area	○	○	○	○	○
Indoor therapy area (PT, OT, art, music)	○	○	○	○	○

Please turn to next page.

The Impact of Facility Design on Social Support and Interaction for Adolescents with Cancer: Questionnaire

Next I'm going to ask about your relationships with other people while you were receiving treatment. Based on your experience when you were last treated, please tell me how much the statement described your situation.

	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree
I feel responsible for taking care of someone else	○	○	○	○	○
I am with a group of people who think the same way I do about things	○	○	○	○	○
I do not think that other people respect what I do	○	○	○	○	○
If something went wrong, no one would help me	○	○	○	○	○
I have close relationships that make me feel good	○	○	○	○	○
I have someone to talk to about decisions in my life	○	○	○	○	○

Please turn to next page.

The Impact of Facility Design on Social Support and Interaction for Adolescents with Cancer: Questionnaire

Please tell me how much the statement described your situation.

	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree
There are people I know will help me if I really need it	○	○	○	○	○
I do not have close relationships with other people	○	○	○	○	○
There is no one I can turn to in times of stress	○	○	○	○	○
There are people who call on me to help them	○	○	○	○	○
There are people who like the same social activities that I do	○	○	○	○	○
Other people do not think I am good at what I do	○	○	○	○	○

Please turn to next page.

The Impact of Facility Design on Social Support and Interaction for Adolescents with Cancer: Questionnaire

Please tell me how much the statement described your situation.

	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree
There are people who value my skills and abilities	○	○	○	○	○
There is no one who has the same interests and concerns as me	○	○	○	○	○
There is no one who needs me to take care of them	○	○	○	○	○
I have a trustworthy person to turn to if I have problems	○	○	○	○	○
I feel a strong emotional tie with at least one other person	○	○	○	○	○
There is no one I can count on for help if I really need it	○	○	○	○	○

Please turn to next page.

The Impact of Facility Design on Social Support and Interaction for Adolescents with Cancer: Questionnaire

Please tell me how much the statement described your situation.

	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree
There is no one I feel comfortable talking about problems with	○	○	○	○	○
There are people who admire my talents and abilities	○	○	○	○	○
I do not have a feeling of closeness with anyone	○	○	○	○	○
There is no one who likes to do the things I do	○	○	○	○	○
There are people I can count on in an emergency	○	○	○	○	○
No one needs me to take care of them	○	○	○	○	○

Please turn to next page.

Based on your experience when you were last treated (or currently being treated), how much of a problem were these issues for you?

	Always	Most of the time	About half the time	Sometimes	Never
I ache or hurt in my joints and/or muscles	○	○	○	○	○
I hurt a lot	○	○	○	○	○
I become sick to my stomach when I have medical treatments	○	○	○	○	○
Food does not taste very good to me	○	○	○	○	○
I feel too sick to my stomach to eat	○	○	○	○	○
Needle sticks hurt (i.e. injections, blood tests, IVs)	○	○	○	○	○
I get scared about having needle sticks	○	○	○	○	○

Please turn to next page.

Based on your experience when you were last treated (or currently being treated), how much of a problem were these issues for you?

	Always	Most of the time	About half the time	Sometimes	Never
I get scared when I am waiting to see the doctor	○	○	○	○	○
I get scared when I have to go to the hospital	○	○	○	○	○
I worry about the side effects from medical treatments	○	○	○	○	○
I worry about whether or not my medical treatments are working	○	○	○	○	○
It is hard for me to figure out what to do when something bothers me	○	○	○	○	○
I have trouble writing work/school papers	○	○	○	○	○
It is hard for me to remember what I read	○	○	○	○	○

Please turn to next page.

Based on your experience when you were last treated (or currently being treated), how much of a problem were these issues for you?

	Always	Most of the time	About half the time	Sometimes	Never
I feel I am not good-looking	○	○	○	○	○
I don't like other people to see my scars	○	○	○	○	○
I am embarrassed when others see my body	○	○	○	○	○
It is hard for me to tell nurses and doctors how I feel	○	○	○	○	○
It is hard for me to ask the doctors and nurses questions	○	○	○	○	○
It is hard for me to explain my illness to other people	○	○	○	○	○

Please turn to next page.

Optional: Please provide additional comments of the topic of AYA cancer here.

_____

_____

_____

Optional: Please provide the name and location of one or more cancer facilities that you have found to be especially well-designed.

_____

_____

If you would like to receive a $10 Amazon gift card for your participation, please provide your email address below. It will not be associated IN ANY WAY with your responses to the survey.

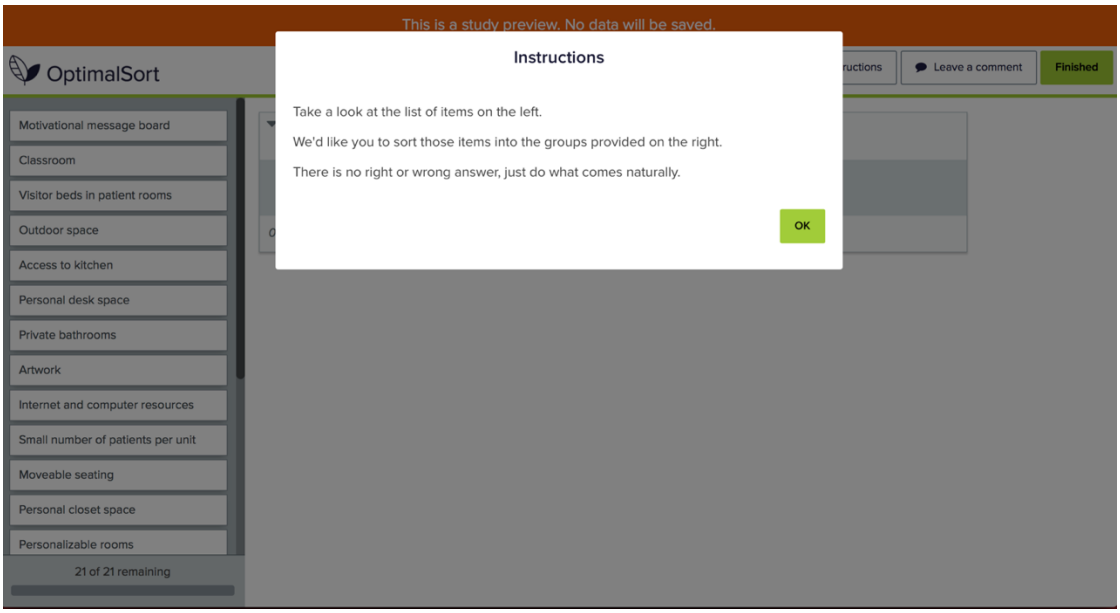
Email: _____

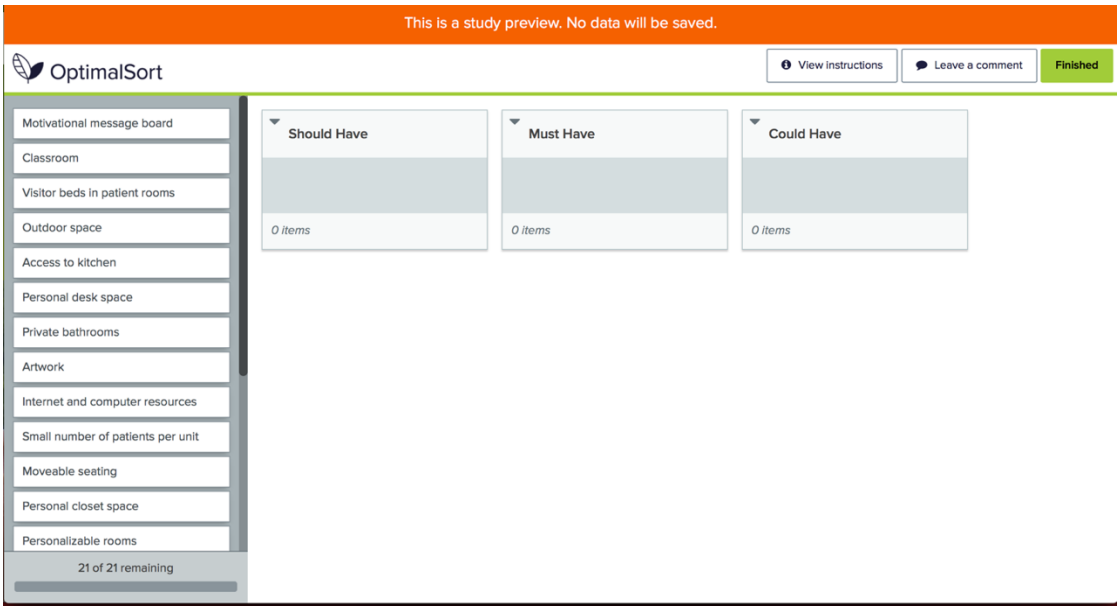
Are you interested in being contacted for future studies involving adolescent and young adult cancer? Your contact information will not be shared with any other researchers except the Principal Investigator of this study.

- ○ Yes, please save my email address for future studies.
- ○ No, please do not contact me about future studies.

APPENDIX C

Online Sorting Task for Virtual Focus Groups (Chapter 4)

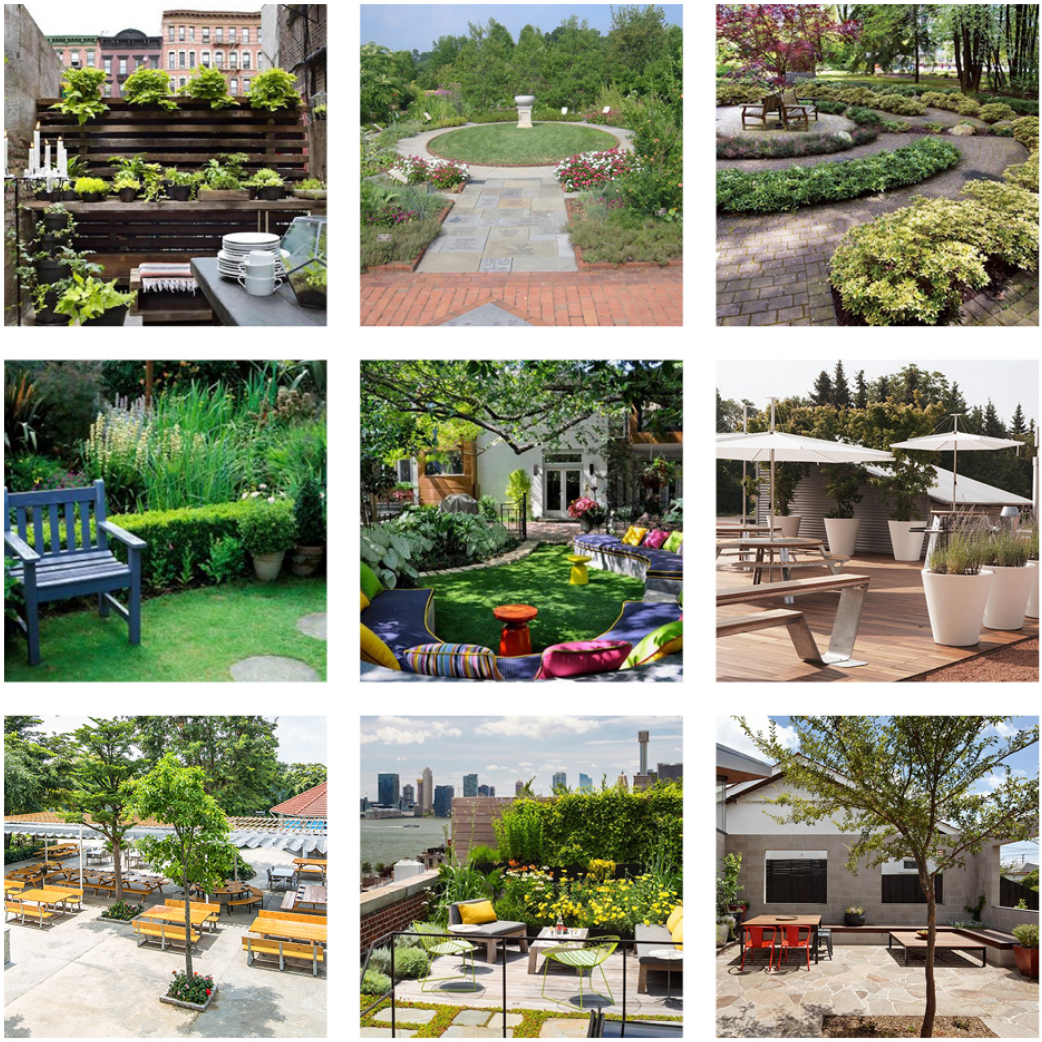




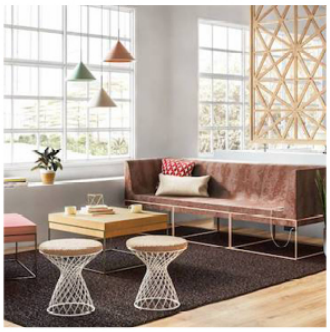
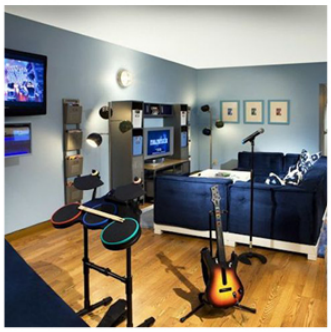
APPENDIX D

Photo Grids for Evaluation (Chapter 4)

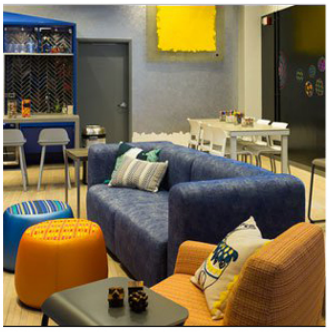
OUTDOOR SPACE



LOUNGES



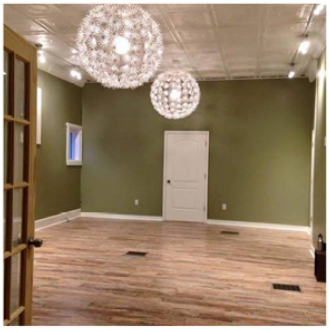
MEDITATIVE SPACE











PATIENT ROOMS